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ABSTRACT

Although this training manual was developed as a tool for trainers of African American and rural family caregivers of elders with dementia, it can easily be adapted for trainers of caregivers (both formal and informal) of persons other than those with dementia. The first section educates potential trainers about dementia, rural issues, ethnic competence, adult learning theory, and strategies for conducting workshops. An extensive list of references accompanies most chapters. Tips for trainers, suggestions for outreach, a sample press release, and answers to evaluation (study) questions are also included in this section. The second section consists of comprehensive lesson plans sequenced according to the progression of dementia. Its purpose is to provide single-source, ready-to-use materials and to minimize preparation time for trainers. Each lesson plan includes a goal, rationale, educational objectives, lecture information, audio-visual materials, suggested learning activities, and references and suggested readings. The appendix includes information on the Virginia Center on Aging, program replication, and project associates and trainers. (LP)

ED 398 043

Families Who Care

Assisting African American and Rural Families Dealing with Dementia

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Mother and I share a joke

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Theodore has a good day

Edited by

Constance L. Coogle
and
Ruth B. Finley

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Families Who Care: Assisting African American and Rural Caregivers Dealing with Dementia

Virginia Center on Aging

in cooperation with

Virginia Geriatric Education Center

Families Who Care:
Assisting African American and Rural Caregivers Dealing with Dementia

A Training Manual

Edited by

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ABOUT THE PHOTOGRAPHER

Carlie Collier is a Richmond-based free-lance artist/photographer who specializes in black and white and hand-colored photography. She took the photographs of caregiving families on the cover and inside the training manual. Carlie teaches photography courses and workshops on the East Coast, and her personal work has been exhibited widely. Her recent thesis project for a master's degree in fine arts was a photo exhibit entitled "MUSES: A Tribute to Mature Women Who Live Creative Lives." "MUSES" celebrates and reveals strong vital women who have chosen to let creativity and the process of aging facilitate their becoming more fully themselves.

In discussing the artistry involved with the caregiver photography for this manual, Carlie feels "almost Messianic about expressing the strength, devotion and compassion of caregivers. In spending some time with our featured caregiving families, I've tried to 'catch' them in typical activities of daily life. Even the care recipients, who had no idea who we were or what we were about, seemed to sense that this was a good thing and enjoyed the experience, opening up to my camera."

DEDICATION

This training manual is dedicated to the
African American and rural family caregivers who
attended the workshops conducted.
Their willingness to share their joys and sorrows with
other caregivers and the project's trainers
enriched the experience for all involved.
The efforts of project staff, advisory groups, and trainers
were intended only to support these faithful, seemingly tireless individuals.

About the Editors and Project Staff

Constance L. Coogle, Ph.D. is the Manager of Information Systems at the Virginia Center on Aging (VCoA) with joint appointments in the Departments of Psychology and Gerontology at Virginia Commonwealth University. She has served the Alzheimer's Association - Greater Richmond Chapter since 1991 as Secretary and Chair of the Medical and Scientific Advisory Committee.

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Edward F. Ansello, Ph.D. is Director of the VCoA. He has worked on rural issues since 1979, beginning with a project on rural recreation funded by the U.S. Department of the Interior. He co-directed three projects on rural geropharmacy (medications and aging) supported by the Andrus Foundation, and one (1991-1993) supported by the VGEC. His rural publications include a Special Issue on Rural Aging for the journal, Educational Gerontology (1980) and coeditorship of a manual for elder caregivers on medication management (1988). He served as a first level "trainer of trainers" for one of the training programs, discussing special considerations for trainers of rural caregivers.

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About the Centers

The Virginia Center on Aging (VCoA) was established by the Virginia General Assembly in 1978 as a statewide university-based Center for interdisciplinary study, research, and information sharing. Located in Richmond at **Virginia Commonwealth University**, the Center's operational focus is applied gerontology, and it provides education, research, training, services, and technical assistance to meet the challenges of achieving healthy and meaningful living in later years. In 1982 the General Assembly established the Alzheimer's and Related Diseases Research Award Fund to stimulate multidisciplinary research in Virginia, and authorized the VCoA to administer the program. Since then, a total of 48 awards have been made in the areas of biomedical, psychosocial, and sociological study.

The Virginia Geriatric Education Center (VGEC) was established in 1985 at **Virginia Commonwealth University**. Its mission is to promote and enhance geriatric education and curricula in Virginia. The VGEC provides comprehensive educational services and materials to professionals involved in the health care of older adults. The activities are carried out with the cooperation of the Schools of Medicine, Nursing, Dentistry, Pharmacy; the Virginia Center on Aging; the Virginia Institute for Developmental Disabilities; the Office of Continuing Studies and Public Service; University Library Services; the McGuire Department of Veteran Affairs Medical Center; and in cooperation with medical consortium schools at the University of Virginia and Eastern Virginia Medical School.

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The editors wish to express their appreciation to everyone involved in the compilation, preparation, and production of this training manual. First and foremost we are most grateful to the U.S. Administration on Aging (AoA) for issuing the initiative and providing the bulk of the funds for the project, which was the genesis of the manual. Our Project Monitor at AoA, Bruce Craig, has been a consistent source of advice and encouragement throughout the project. His faithful guidance and sense of humor continually sustained and nourished our dedicated enthusiasm to the project goals and objectives.

The direction and editorial assistance in preparing the grant application provided by our colleague, Edward Ansello, was invaluable. We especially want to thank those who directly contributed Chapters or Caregiver Lesson Plans to the manual:

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We are additionally indebted to members or our two advisory groups, the Central Virginia and Southside Virginia Regional Needs and Resources Teams (see listings of Regional Needs and Resource Team members in Appendix). These individuals shaped the content of the manual through a process of group consensus-building, in addition to other advisory responsibilities. Other members of the project staff (Drs. Edward Ansello, Michael Pyles, and Joan Wood) and office assistants (Sheryl Lutz and Kathy Lanier) should also be acknowledged for their

contributions to the manual. The photographer (Carlie Collier, M.A.) and her subjects (Mr. and Mrs. Theodore Patron, Ms. Dorothy Morris and her mother, Mrs. Lillie Wyndham) are acknowledged for volunteering their time and effort, as is the graphics designer, Diana Plasberg.

We would be remiss not to mention our trainers who volunteered to be the recipients of our instruction, master the training manual, and conduct caregiver workshops (see listing of Trainers of Caregivers in Appendix). These community leaders, who so generously gave of their time so that others could benefit, constitute the manual's *raison d'etre*. We cannot thank them enough for their willingness to participate in the project and provide education for African American and rural family caregivers. Finally, we wish to acknowledge the efforts of family caregivers everywhere. It is primarily through their courage, strength, and selfless determination, that older adults with disabilities can remain in their homes continuing to enrich the lives of their loved ones and others in the community.

C.L.C. & R.B.F.

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Part I

Training for Trainers: Educational Chapters

Ethel Patron had spent more than 43 years in the nursing profession before retiring due to physical disability. Shortly thereafter she began providing fulltime care for Theodore, her husband of 41 years. Mr. Patron, who is blind, was diagnosed several years ago with Alzheimer's Disease and Parkinson's Disease. The Patrons are pictured here in their church, Fifth Baptist Church of Richmond, where Mrs. Patron received a plaque a few years ago denoting 50 years of membership, and more recently, a Life Membership in the Mission Society. No stranger to compassion, Mrs. Patron's mission work has benefitted children, families in need, and nursing home residents. Not surprisingly, she provided a "nurse's chair" which bears her name and now sits on the platform at Fifth Baptist. It stands as a historical reminder of the many years that she, along with other nurses in the congregation, both past and present, have been on duty during worship services. In speaking of the role that her church has played, especially during her caregiving years, Mrs. Patron says, "The church has been helpful in all ways. Not only have its members been concerned about Theodore's status, but they have been concerned about me, particularly since my shoulder surgery. The Deacons bring communion to us at the house since we can't get out to services anymore. The Deaconesses visit at least once a month, and someone phones me almost every night. As a caregiver, I pray for the patience to go slow and not get mad or agitated with Theodore. It's becoming more and more difficult, but I know that people in my church are praying for us."

Carlie Collier

INTRODUCTION

OVERVIEW: THE BIG PICTURE

Alzheimer's Disease is more common now than in the earlier years of this century because more people than ever before are living to the age of risk. About 10% of those over 65 years of age have Alzheimer's Disease; above the age of 85, it has been estimated that almost half may develop the Disease. To make matters worse, as the number of older persons increases, so will the number of persons with AD. This also means that the number of lay and professional caregivers will necessarily increase dramatically. **Chapter 1 provides more information about Alzheimer's Disease and other dementias as well as caregiver issues.**

Research has consistently shown that community services are under-used by those caring for individuals with dementia, whatever their residence or ethnic background (Caserta, Lund, Wright, & Redburn, 1987; Gwyther, 1988; Lawton, Brody, & Saperstein, 1989; MaloneBeach, Zarit, & Spore, 1992; Yankelovich, Skelly, White, Clancy, Schulman, Inc., 1986). Caregivers of relatives with dementia have concerns about the ability of service providers to understand the particular needs of demented persons (Office of Technology Assessment, 1987, 1990). Often, families simply prefer to be self-reliant and regard the use of formal services as unacceptable (Collins & King, 1990; Deimling, Noelker, & Chernin, 1988; Eckert & Smyth, 1988; Montgomery & Borgatta, 1989; Wilson, 1989). These attitudes are counter-productive, however, and will eventually result in caregiver "burn-out." Convincing family caregivers to access the help that is available will reduce caregiver stress and improve the quality of care they provide.

The Fourth Report of the Advisory Panel on Alzheimer's Disease to the U.S. Congress and the U.S. Department of Health and Human Services calls for "public education and outreach efforts specifically targeted to ethnic elders and their families and communities through the development and dissemination of culturally relevant materials emphasizing both the established facts about [Alzheimer's Disease and Related Disorders] and the efficacy of seeking treatment" (Advisory Panel on Alzheimer's Disease, 1992, p. 50). There is a similar need to train family caregivers of rural elders with dementia, whose informational and service needs may be greater than their urban counterparts. While some of the inequities have been addressed by federal financing and state initiatives, rural and minority elderly and their family caregivers remain under-served.

Our purpose in developing this manual is to enable trainers to provide family caregivers with sequenced training which corresponds roughly to the stages of Alzheimer's Disease. Secondly, the training manual specifically targets African American and rural family caregivers. It is designed to be culturally sensitive and literacy appropriate.

African American Family Caregivers

African American family caregivers of those with dementia have a great need for information about Alzheimer's Disease and the availability of community resources (Harel, 1986; Segall & Wykle, 1988). The prevalence rate of dementia may be higher among elderly African Americans (Heyman, Fillenbaum, Prosnitz, & Raiford, 1991). Because rural, African American caregivers of family members with AD are particularly unlikely to seek eldercare information or services (Wood & Parham, 1990), caregiver workshops aimed at this special population are especially needed.

Ethnic and cultural variations may influence family perceptions about the acceptability of seeking help from outside the family (Holmes, Teresi, & Holmes, 1983). African American families are more likely to rely on informal or familial assistance with health and financial problems (Mindel, Wright, & Starrett, 1986; Ulbrich & Warheit, 1989). Yet, older African American women are less likely than their non-minority counterparts to have their needs met by primary family members (Montgomery & Hirshorn, 1991).

Several barriers affect service utilization among minority elders and their families. These include:

1) actual or perceived racial discrimination;
2) a lack of familiarity with services and providers;
3) fear or suspicion of agencies providing services;
4) cultural "sacred cows," which make service use incompatible with beliefs and values of the individual, e.g., "we take care of our own";
5) a lack of service providers trained to be especially sensitive to minority issues; and
6) a lack of minority involvement in service planning and needs assessment.

Impoverished African American families have adopted a number of adaptive behaviors to deal with low income situations that have persisted for generations in some cases. These behaviors make it difficult for them to seek out formal assistance. There is some suggestion that the effective provision of services to minority elders must be planned and executed in new and creative ways. "To accept the fact that the Black elderly experience problems differently or more intensely because of the additional impact of racial discrimination is to suggest perhaps public provision of resources should be handled differently for them" (Rathbone-McCuan & Hashimi, 1982, p. 117). **Chapter 2 is devoted to developing ethnic competence among trainers of African American caregivers.**

Rural Family Caregivers

The incidence of dementia in non-metropolitan areas is probably the same as in metropolitan areas. It is likely that dementia is under-diagnosed in rural areas however, since specialized diagnostic and evaluative services are not as available. Rural family caregivers of elders with AD are less likely to seek out information about their problems, and they receive less emotional support from their family and friends (Wood & Parham, 1990).

There are fewer health services (Coward & Cutler, 1989; Krout, 1986; Taietz & Milton, 1979), community-based aging services (Krout, 1991, 1993; Nelson, 1980, 1983; Taietz & Milton, 1979), and mental health services (Wagenfeld, 1990) available to rural elders. Even when services are available, they are under-utilized by rural elders and their families because they are not accessible (Blieszner, McAuley, Newhouse, & Mancini, 1987; Bull, Howard, & Bane, 1991; Wagenfeld, 1990). Certain barriers to service are especially problematic in rural areas (Coward & Rathbone-McCuan, 1985; Ecosometrics, 1981; Krout, 1993; McCulloch & Lynch, 1993). These include:

1) limited communication about service availability due to poor telephone communication systems, larger service areas requiring toll calls, and homes without telephones;
2) geographic isolation, poor roads, and the lack of any public transportation;
3) client eligibility restrictions and unresponsive administrative practices;
4) the fear of stigma attached to mental illness;
5) a failure to recognize that services are needed;
6) negative attitudes about receiving outside assistance;
7) fears associated with the loss of independence; and
8) a lack of understanding about bureaucratic procedures.

These barriers are compounded by long years of remoteness from mainstream community-based programs. Historically, rural families "struggled alone" without the benefit of any outside assistance. A common response when families are approached for the first time with an offer of assistance may be, "Where have you been before now?" **Chapter 3 explores these rural barriers to service in more detail and offers tips for trainers on how to overcome them.**

Although this manual was developed as a tool for trainers of African American and rural family caregivers of elders with dementia, it can be easily adapted for trainers of caregivers (both formal and informal) of persons other than those with dementias. Some of the information is relevant to those who care for disabled elders, whether or not they have a cognitive deficit. Because this manual contains two Chapters pertaining to the ethnic and rural aging experiences, it can additionally be used within the field of aging to increase sensitivity about these two special populations. **Chapter 4 deals with effective training methods for adults and Chapter 5 provides specific instructions on recruiting caregiver trainees, conducting sessions, and evaluating the outcome.**

CONTENT PREVIEW: TWO PARTS, TWO PURPOSES

This manual is organized in two parts. **Part I (Training for Trainers)** has five chapters and its purpose is to provide basic information about the content matter and the people to be trained. These chapters were specifically written with your caregiver trainees in mind. They are designed to educate trainers about dementia, Alzheimer's Disease, caregiving, ethnic competence, rural considerations, adult learning theory, and how to conduct workshops.

The **first chapter** provides basic information about Alzheimer's Disease and other dementias, with special attention to caregiver issues. It is foundational to the whole training. It paints a picture with broad strokes. All of the Caregiver Lesson Plans (see Part II) radiates from this base. The chapter focuses on the relation between the person with AD, the caregiver, and the disease itself. The content is up close and personal. The training is designed to meet the needs of caregivers where they are "at" emotionally on a day-to-day basis. Consequently, related topics such as research, advocacy, and public policy, although important, are not included.

The **second chapter** focuses on African American caregivers with a discussion of how culture and ethnicity impact the aging process. **Chapter 3** gives specific information about the differences between elderly populations in rural and urban areas, noting special considerations important to trainers of rural caregivers.

The **fourth chapter** instructs trainers on how adults learn with an overview of adult learning principles and theories. It is especially important. With adult students, the trainer is essentially the "lead learner" or facilitator, not a fount of knowledge flowing into untutored minds. Adults, especially middle and older ones, have a store of experience, values, and motivations, and they have come together to deal with a common problem: providing care for a loved one (or maybe not-so-loved but someone for whom they feel responsible) who has been diagnosed with a disease they may know little about. Trainers who draw out caregivers and prompt them to share their knowledge and experience will enrich the workshop for all. Caregivers can derive a great deal of comfort from realizing they're not alone. Group problem-solving can be quite efficacious! Some caregivers may have developed some ingenuous methods of dealing with a problem that is, or will be, faced by other caregivers as well. By sharing their solutions and coping methods, they are able to help others in the group become better able to deal with the problematic situations that arise. The "tools of the trade" discussed in the last half of the fourth chapter, enable the astute trainer to "pick and choose" those methods which offer the best fit for the group.

The **last chapter** explains in detail exactly how to recruit caregivers, find a meeting site, and publicize the workshops. It provides step-by-step instruction on how to conduct each caregiver workshop.

Part II (Training for Caregivers) contains Caregiver Lesson Plans, organized in modular format. Its purpose is to provide single-source, ready-to-use materials and to minimize preparation time for trainers. The reading level of each module is given in the Table of Contents. The editors have made an effort to simplify the lecture information as much as possible. Since the lecture is intended to be delivered orally, the material is given gramatically in both the second and third persons. The order of the modules roughly corresponds with the progression of the cognitive, social, and behavioral impairments accompanying Alzheimer's Disease and other dementias. The first group of lesson plans (Modules 1-6) concerns issues important during the early stages of dementia; the second group (Modules 7-17) deals with topics that arise during the middle stages; and the third group (Modules 18 & 19) focuses on problems associated with the later stages of dementia. The idea is to allow caregivers to obtain the information and resources they need, **when** they need it the most. More detail about how to use the Caregiver Lesson Plans is provided in Chapter 5.

A PERSONAL CHALLENGE TO TRAINERS

At this point, you may be wondering if you can become a trainer. The bottom line is, "If you care, you can." If you sincerely believe you can improve the quality of life for caregivers and those for whom they care, you can overcome stereotypes and prejudices you may have grown up with. You have the ability to facilitate an increase in knowledge, a change in attitudes/behaviors, and the development of skills through training.

Before you can train, you have to recruit trainees. Indeed, recruitment and training are two sides of the same coin. Half (or more!) of the job of trainers in this project is to recruit reluctant family caregivers to attend the sessions. You must convince them that you can offer information vital to their particular situations. Therefore, when recruiting caregiver participants, trainers should emphasize the fact that multiple sessions corresponding to the progression of dementia will be offered. Encourage potential participants to attend all sessions, but don't exclude them if they can't. Similarly, publicity regarding caregiver workshops should be detailed enough to assure potential participants that the sessions will be targeted to their unique needs and will allow sufficient opportunity for questions to be answered.

By the time you start your workshop sessions, you will have read all five chapters carefully and applied much of what you have learned. Basic to training is an understanding of the family caregivers -- their strengths and weaknesses; their burdens and rewards; and their unique relationships with those for whom they care. It is to these persons -- family caregivers -- that this manual is dedicated. The project staff, advisory groups, and trainers exist only to support these faithful, tireless individuals.

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CHAPTER 1: DEMENTIA AND CAREGIVING ISSUES[1]

WHAT IS DEMENTIA?

Dementia is the loss of intellectual functions (such as thinking, remembering, and reasoning) of sufficient severity to interfere with an individual's daily functioning. Dementia is not a disease itself, but a group of symptoms that may accompany certain diseases and conditions. For a diagnosis of dementia there must be impairment of short and long term memory, and at least one of the following symptoms: 1) changes in personality, mood, and behavior; 2) difficulty with problem solving and abstract thinking; 3) impaired judgment; or 4) specific disturbances of higher brain functioning. These disturbances must significantly interfere with the social activities or relationships, and there must be evidence of an organic or physical cause (Arizona Long Term Care Gerontology Center, 1990; Alzheimer's Association, 1992).

Dementia is NOT a normal part of aging. It is NOT hardening of the arteries and it is NOT "senility." There are over 50 causes of dementia, many of which are reversible. For example, dementia can be due to:

1) medications (e.g., reactions, interactions, non-compliance, abuse, misuse);
2) alcohol misuse or abuse;
3) hypothyroidism;
4) vitamin deficiency (especially Vitamin B-12);
5) depression;
6) brain tumor;
7) blood clot; or
8) hormone imbalance.

Because there are so many causes of dementia, it is critical that caregivers obtain a thorough evaluation and diagnosis for their loved ones who exhibit symptoms of AD. If the condition is reversible, immediate attention is imperative. It's important to remember, however, that the dementia caused by Alzheimer's Disease and some related diseases (Creutzfeldt-Jakob, Pick's, Parkinson's, etc.) is not reversible.

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[1] Sheryl Lutz is gratefully acknowledged for her assistance with this Chapter.

WHAT IS ALZHEIMER'S DISEASE?

Defined

A progressive, age-related, chronic cognitive dysfunction, Alzheimer's Disease is the most common form of dementia. It is a progressive, degenerative disease that attacks the brain and results in impaired memory, thinking and behavior. It affects as many as four million adults in the United States.

Alzheimer's Disease usually has a gradual onset. Problems remembering recent events and difficulty performing familiar tasks are early symptoms. The person with AD also may experience confusion, personality change, behavior change, or impaired judgement. Difficulty finding words, finishing thoughts or following directions may also be indicative of Alzheimer's Disease. How quickly and the extent to which these changes occur, will vary from person. Eventually, however, the disease leaves individuals totally unable to care for themselves.

Alzheimer's Disease causes cells in the brain, called neurons, to die. The brain shrinks, the grooves on the surface become larger, and the spaces (called ventricles) get bigger. In addition, neurofibrillary tangles and neuritic plaques appear. Neurofibrillary tangles are twisted fibers inside the brain cells. As more tangles are formed, the cell "sickens and dies." Neuritic plaques are formed from broken parts of neurons. Plaques interfere with a brain cell's ability to receive and transmit messages to other neurons. Plaques and tangles are concentrated in the hippocampus, the structural part of the brain associated with short term memory (Reisberg, 1981). There are also changes in the neurotransmitters, or the chemicals which allow brain cells to talk with each other. One major neurotransmitter affected by Alzheimer's Disease is acetylcholine, which plays an important role in memory and thought processes.

The most conclusive diagnosis can be **confirmed** only upon examination of brain tissue at autopsy. On microscopic examination, areas of the brain responsible for memory and intellectual functions are found abnormal. The classic pathological hallmarks of Alzheimer's Disease are the presence and **quantity** of plaques and tangles, because the atrophied brain of normally functioning elders also has some degree of plaques and tangles. Currently there is no treatment available to stop or reverse the mental deterioration characteristic of Alzheimer's Disease. Until the genesis of Alzheimer's Disease is known, there will be no way to prevent it.

History

Because of recent widespread publicity about Alzheimer's Disease, many people wonder if it is a new disease and, if not, how long ago it was identified. References to older people with confusion and memory loss can be traced as far back as 500 B.C. More recently, in 1835, a physician named James C. Prichard described short term memory loss in older people as "incoherence" or "senile dementia." European investigators reported "cerebral plaques" in 1892. When Dr. Alois Alzheimer reported on the relationship between brain pathology and the behavioral symptoms during life, his name became attached to the disease. More recently, Corsellis and Evans (1965) distinguished AD as a dementia characterized on autopsy by specific brain abnormalities.

WHAT ARE THE TYPES OF DEMENTIA?

(Alzheimer's Disease & Related Disorders Association, 1991).

Although Dementia of the Alzheimer's Type is the most prevalent, there are related dementias, as follows:

Multi-Infarct Dementia. Multi-infarct dementia (MID), or vascular dementia, is mental deterioration caused by multiple strokes (infarcts) in the brain. The onset of MID may be sudden and many strokes can occur before symptoms appear. These strokes may damage areas of the brain responsible for a specific function (e.g., calculations). There may also be more generalized symptoms, such as disorientation, confusion, and behavioral changes. As a result, MID may appear to be similar to Alzheimer's Disease. MID and Alzheimer's Disease coexist in 15-20% of persons with dementia. Brain scanning techniques (CAT, MRI) are used to identify strokes in the brain. MID progresses in a step-wise fashion, with periods of stability or even slight improvement between strokes. Histories of high blood pressure, vascular disease, diabetes, or previous strokes have been identified as risk factors. MID is not reversible or curable. Recognition of an underlying condition (e.g., high blood pressure) may lead to specific treatment, however.

Parkinson's Disease. Individuals with Parkinson's disease lack the substance dopamine, which is involved in control of muscle activity by the nervous system. Tremor, stiffness, and slowness are characteristic features of Parkinson's disease. Speech may be slow. Movement may be difficult to initiate. Late in the course of the disease, some individuals develop dementia. Some people with Parkinson's disease develop Alzheimer's Disease, and some individuals with AD develop symptoms of Parkinson's disease. Drugs can improve motor symptoms,

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but do not improve the mental changes that occur. In fact, Parkinson's disease serves as a model for drug research on Alzheimer's Disease.

Huntington's Disease. Huntington's disease is a hereditary disorder that usually begins in mid-life and is characterized by irregular involuntary movements of the limbs or facial muscles and intellectual decline. Psychiatric problems are common, with depression and memory disturbances occurring in early stages. The pattern of memory impairment differs from that seen in Alzheimer's Disease. As the disease progresses, movements become severe and uncontrollable; mental capacity may deteriorate. The family history of the disease, recognition of typical movement disorders, and brain scanning provide evidence for a diagnosis of Huntington's disease. A genetic marker linked to the Huntington gene has been identified on chromosome four. Researchers are working on locating the gene itself. The movement disorders and psychiatric symptoms seen in Huntington's disease can be controlled somewhat by drugs. However, no treatment is available to stop the progression of the disease.

Creutzfeldt-Jakob Disease. Creutzfeldt-Jakob disease is a rare fatal brain disease caused by a transmissible infectious agent, possibly a virus. Failing memory, changes in behavior, and a lack of coordination are observed in the early stages. The disease progresses rapidly, usually causing death within one year of diagnosis. Examination of brain tissue reveals distinct changes unlike those seen in Alzheimer's Disease. Just as in Alzheimer's Disease, however, no treatment is currently available to stop the progression of the Creutzfeldt-Jakob disease.

Pick's Disease. Pick's disease is a rare brain disease which closely resembles Alzheimer's Disease and is usually difficult to diagnose clinically. Disturbances in personality, behavior, and orientation may precede, and initially be more severe than, memory defects. Like Alzheimer's Disease, a definitive diagnosis is usually obtained only at autopsy.

Normal Pressure Hydrocephalus. Normal pressure hydrocephalus is an uncommon disorder that consists of difficulty in walking, dementia, and urinary incontinence. An obstruction in the normal flow of the spinal fluid causes the fluid to build up. Presently the most useful diagnostic tool is the MRI scan. Possible factors are a history of meningitis, encephalitis, and head injury. Besides treatment of the underlying cause, the condition may be improved by a neurosurgical procedure (shunt), which is a tube placed in the head that diverts fluid outside the brain.

Depression. Depression is a psychiatric disorder marked by sadness, inactivity, difficulty in thinking and concentration, feelings of hopelessness, and sometimes suicidal tendencies. Many severely depressed people will have some mental deficits including poor concentration and attention. When dementia and depression are present together, intellectual deterioration may be exaggerated. Depression, whether present alone or in combination with dementia, can be reversed with proper treatment.

HOW IS ALZHEIMER'S DISEASE DIAGNOSED?

(Boyd, Frieden, Higley, & Spencer, 1989)

Alzheimer's Disease is diagnosed by excluding other possible causes for the behavior. Since there is no one test to identify the disease, a battery of tests must accompany a complete physical exam. Neurological exams such as computerized axial tomography (CAT) scan, magnetic resonance imaging (MRI), or electroencephalogram (EEG) may be required, in addition to psychological and/or psychiatric examinations. Detailed family and social histories should be taken to identify any drug or alcohol problems or medical problems which "run in the family" and may cause signs of dementia. By ruling out other causes for the dementia symptoms, a diagnosis of Alzheimer's Disease can result with some degree of certainty.

WHAT IS THE COURSE OF THE DISEASE?

(Boyd, Frieden, Higley, & Spencer, 1989; Bayles, 1991; Gwyther, 1985; Caregivers practical help: Caring for Alzheimer's patients, 1988; Alzheimer's 101: The basics for caregiving, 1989; Vermeersch, Greene, & Meade, 1988).

Knowledge of the symptoms of Alzheimer's Disease can aid in the early identification of affected individuals. Early identification can help persons with AD and their families prepare for the caregiving responsibilities ahead. Data about the order of appearance of Alzheimer's Disease symptoms are scarce. By the time medical attention is needed, the care recipient may be unable to recount the order in which symptoms appeared (Folstein & Powell, 1984; Rubin, Drevets, & Burke, 1988; Sim, 1965; Sim & Sussman, 1962; Sim, Turner, & Smith, 1966). The best source of information is the primary caregiver, but only a few investigators have studied their perceptions of when symptoms appear.

There is a great deal of individual variation in which abilities are lost and which are retained, the order in which symptoms appear, and how long they last. While no two people exhibit the same symptoms, there are some common characteristic behaviors. Since Alzheimer's Disease is the most common cause of dementia, it is used as a model for the progression of cognitive and behavioral changes which occur with dementing illness. The course of Alzheimer's Disease is often described in terms of early, middle, and late stages. The symptoms associated with each stage develop over time, and the stages, along with their basic symptoms, often overlap. Trainers must realize, and should emphasize to caregivers, that the disease process is not predictable or uniform. **The description of stages provided here should be taken as general guidelines and not as an exact prognosis.**

Earlier Stages (The "Forgetfulness Phase" - Typically lasts from 2-4 years)

In the earlier stages of the disease, the person with AD may know something is wrong but denies it to others. Often symptoms are overlooked or dismissed. Although the affected individual is usually the first to notice a problem, eventually the family and close friends become aware that "something is wrong." Often the symptoms are first noticed after the person has been stressed. A change in residence, illness, or even taking a trip can be taxing for someone in the earlier stages of dementia. Often a crisis occurs and forces family members to seek a medical evaluation.

Forgetfulness is the primary symptom. There is a loss of recent or short-term memory. **It's important to realize that memory loss alone is not a sign of Alzheimer's Disease**. Many people experience some difficulty remembering things as they age. In Alzheimer's Disease, however, the problem becomes steadily worse and is accompanied by other symptoms. There may be subtle personality changes and signs of depression.

Below are some of the cognitive and functional changes during the earlier stages.

* Decreased ability to concentrate
* Mild confusion
* Some disorientation as to time and/or place
* Impaired judgement
* Difficulty with complex, but familiar tasks
* Mild communication problems
* Loss of initiative
* Lack of spontaneity
* Increased anxiety
* Increased dependence on others
* Decreased energy
* Mood swings

* Mild depression
* Denial

Below are some examples of how these cognitive and functional changes may affect behavior.

* Forgets which bills are paid; may pay bills more than once or not at all
* Forgets phone numbers that are often dialed
* Arrives for an appointment at the wrong time or place
* Goes out without a coat in winter
* Forgets what he or she has just been told, and denies forgetfulness
* Misplaces familiar items (e.g., keys, wallet)
* Gets lost in formerly familiar surroundings
* Loses track of time
* Exhibits anomia, (i.e., inability to think of words or names)
* Makes frequent irrelevant comments
* Has trouble expressing ideas
* Has difficulty understanding the ideas of others
* Becomes less outgoing or declines invitations
* Hides things
* Accuses others of stealing or hiding things
* Blames others for personal inadequacies
* Resists starting new projects or engaging in new activities
* Seems to have lost the "zest for life"
* Takes longer with routine chores
* Withdraws and seems disinterested or unaware
* Avoids contact with others
* Has careless appearance or attitude
* Seems out of sorts
* Gets upset easily
* Over-reacts to criticism, situations
* Seems sadder
* Sleeps too much or too little
* Loses an unusual amount of weight
* Is more quiet or more negative than usual
* Perseverates, i.e., engages in repetitive, continuous activity (e.g., lip-smacking, lip-licking, chewing, tapping)

While there is some decline in psychological ability during the earlier stages, it's important to remember that some competencies remain unaffected. Persons with AD may still be able to learn new things and perform daily care activities with little or no assistance. In addition, the mechanical aspects of speaking and reading are retained, and they are usually able to correct mistakes in speech.

People who live independently are increasingly vulnerable during the earlier stages of Alzheimer's Disease. The inability to recall significant personal information is not only frustrating, but dangerous for the forgetful individual. Accidents are not uncommon, since continuity of thought is disrupted. Denial is a powerful defense mechanism, protecting the person with AD from coming to terms with their condition. Eventually it becomes apparent that something is terribly wrong. The result is anger, suspicion, and periodic crying. The onset of mild but continuous depression is a good indication that the formerly functional defense mechanism has failed. At this point there is a need for medical intervention, since there is effective treatment for the symptoms of depression.

Middle Stages (The "Confusional Phase" - Typically lasts from 2-12 years)

As the disease progresses, persons with AD can no longer hide their symptoms from others. Memory losses become more frequent and more profound. There is little doubt that a serious problem exists. By the end of this phase, the care recipient has lost nearly all recent, and some remote (past) memories. Individuals in the middle stages become easily confused and many cannot be left alone. Personality changes during the middle stages may be striking. Anger and frustration can accompany deficits in the ability to perform activities of daily living. Hostile behavior (i.e.,"acting out") may be the consequence of being unable to understand things or make oneself understood. An inability to figure out and cope with the world can lead to extreme nervousness and anxiety.

Below are some of the cognitive and functional changes during the middle stages.

* Memory deterioration
* Recognition ability impaired
* Moderate to severe communication difficulties
* Language deficits
* Poor judgment
* Significant confusion
* Compromised functional ability
* Indecisiveness
* Lack of concentration
* Shortened attention span

* Impaired comprehension
* Disorientation as to time, place, and/or person
* Lack of coordination
* Deterioration of perceptual motor skills
* Logical reasoning impaired
* Calculating ability impaired

Below are examples of how cognitive and functional changes may affect behavior during the middle stages.

* Forgets personal history
* Forgets familiar names
* Is unable to recognize family and friends
* Requires assistance with activities of daily living (ADLs)
* Cannot follow multiple step instructions
* Seems unable to make decisions
* Cannot balance checkbook
* May dress inappropriately
* Demonstrates frequent anomia (i.e., unable to think of words or names)
* Fails to understand written or spoken words
* Cannot follow complex conversations or instructions
* Uses cliches to fill gaps in conversation
* Continually repeats particular movements, statements, or questions
* Uses words illogically
* Wanders and gets lost easily
* Cannot remember recent experiences/occurrences
* Makes up stories to fill gaps in memory
* Cannot follow written signs
* Falls or bumps into things frequently
* Has difficulty with intentional movement (e.g., setting the table)
* Shows occasional muscle twitching or jerking
* Has trouble getting into and out of chairs/bed
* May have visual and/or auditory hallucinations
* May be extremely nervous, anxious, worried, or irritable
* Is restless
* Exhibits loss of impulse control
* Demonstrates paranoia, suspiciousness
* Has frequent mood swings
* Is prone to emotional/behavioral outbursts
* Has significant confusion
* Exhibits disturbances in eating patterns and manners

* Displays hyperorality (i.e., increased need for oral stimulation)
* Hides and hoards things
* Accuses others of stealing/hiding things
* Awakens frequently at night; may get up and wander
* Acts childishly
* Undresses at inappropriate times or in the wrong places
* Acts in a socially unacceptable manner
* Seems insensitive to others
* May display huge appetite for junk food and other people's food; forgets when last meal was eaten, then gradually loses interest in food; chews or tastes available objects
* Gains and then loses weight
* Fatigues more easily; may be lethargic
* Calls for parent who is dead
* Asks to go home when already there
* Has trouble dressing
* Fears bathing
* Becomes easily agitated, paces
* Has toileting problems (usually due to inability to locate toilet, express need, or handle mechanics of toileting)

Many behavioral symptoms which appear in the middle stages are the result of significant chemical changes in the brain. Rather than withdrawing, the person with dementia may become agitated, violent, paranoid, or delusional. Obsessive symptoms, such as performing a simple activity repeatedly, may also occur. It's important to remember that many behavioral symptoms which appear during this phase are medically treatable. Physicians should be consulted about the best methods of treating and coping with mood swings and behavioral disturbances.

Later Stages (The "Dependent Phase" - Typically lasts about 1 year; ends with death)

In the final stages of the disease, those with AD become severely disoriented. Individuals may be physically able to do certain activities, but lack the mental capacity to pursue them purposefully. Late in the disease process there is a flattening of expression or affect. It becomes difficult to tell how they really feel, or if they sense anything at all. This does not mean that they have lost the ability to experience pleasure or pain. There is a tendency to become withdrawn and unresponsive to others. It is sometimes said that the person who "used to be there" no longer exists. Extreme physical disability is not uncommon. True incontinence may also develop. The care recipient eventually becomes completely dependent on the caregiver. Placement in a nursing home is usually necessary because of the scope of care required.

Below are some cognitive and functional changes during the later stages.

* Weight loss even with good diet
* Severe disorientation as to time, place, and person
* No apparent recent (short-term) memory
* Little remote (long-term) memory
* Communication difficulties
* Incontinence
* Marked physical disability
* Prone to seizures
* Immune system deficiency
* Inability to recognize self or others

Below are some examples of how cognitive and functional changes may affect behavior during the later stages.

* Is unable to perform activities of daily living
* Is more susceptible to pneumonia and other viruses, skin infections
* Is unable to smile or swallow
* Has limited or no vocabulary
* Has anomia (difficulty naming objects)
* Has limited ability to communicate non-verbally
* May talk to image in mirror
* Cannot ambulate or only with maximum assistance
* No longer recognizes family members
* Cannot feed self
* Is unaware of environment
* Is usually bed-bound
* Demonstrates hyperorality (increased need for oral stimulation and sucks or chews available objects
* Is extremely irritable or has flat affect (i.e. no personality at all)
* Is delusional or paranoid
* Sleeps more
* Believes place where he resides is not his home or where he should be
* Believes thief is trying to get into the house
* Believes he has been abandoned
* May groan, scream, or make grunting sounds

Brain cell deterioration and denial protect those with dementia from experiencing the full emotional impact in the later stages. Some continue to laugh, smile, and appear happy. There are reports that individuals in the later phase of the disease are still able to attend and enjoy important family events, like graduations or weddings. Human contact is important throughout the course of the disease, even in the very last stages. Attention, consideration, and expressions of love provide emotional and physical stimulation. There is some suggestion that conversation (even if it is completely one-sided) may help enhance orientation to reality.

The caregiver's role is a constantly changing one. At each stage or phase of the disease, there are different needs to be met. The monumental importance of compassionate caregiving and maintaining the person's dignity is a constant imperative from diagnosis to death.

CAREGIVER ROLES IN EACH STAGE OF THE ILLNESS

(Caregivers practical help: Caring for Alzheimer's patients, 1988).

Each stage of the illness brings its own special care problems. In the **earlier stages**, the main problems may be forgetfulness and impairment of learning ability. The caregiver's role is to help find ways to maintain the care recipient's independence as much as possible. Early on, caregivers should educate themselves about the medical, legal and financial aspects of the disease. Most importantly, now is the time to prepare for the physical, psychological and emotional demands of caregiving to come. "An ounce of prevention is worth a pound of cure," and knowing what to expect is half the battle. With careful planning, the caregiver will be able to avert crises and appreciate the positive aspects of caregiving. This is the time to arrange for ongoing medical and custodial care. In short, the early stages are a time to plan for the future.

Safety is a big concern in the **middle stages** of the illness. The memory is failing and judgement is poor. The person with AD may wander or get into things in or around the home that pose a danger. Caregivers may have to watch very carefully. During this stage, the job of caregiving may well expand beyond the abilities of any one caregiver. It's important to set up a network of care arrangements to support the caregiver's efforts during the middle stages.

In the **final stages**, round-the-clock care will be needed. This is the time to consider placing the loved one in an appropriate facility. Placement is a hard choice. Caregivers should talk about it with people they trust who know about making such decisions. Family, friends, a social worker, the clergy, or a doctor may all be able to offer advice at this stage. Whenever placement does occur, these people are already aware of the situation and can provide support.

CAREGIVER BURDEN

Burden refers to the subjective and objective interpretations by the caregiver of an older person's impairments and the impact on caregiving outcomes (Miller, McFall, & Montgomery, 1991). Conceptually, burden is related closely to stress. Another definition of burden is management of the specific tasks to be performed (Pilisuk & Parks, 1988), or objective burden. Stress is most often referred to as the subjective appraisal of caregiver strain (Pilisuk & Parks, 1988), or perceived burden. Stress can be positive and lead individuals to establish their greatest accomplishments. Up to a certain point, increasing stress can improve our performance and efficiency. Stress beyond that point, however, can have a negative effect on us.

Zarit, Reever, and Bach-Peterson (1980) were among the first researchers to study burden in caregivers of demented relatives. Since then, others have confirmed the finding that the care recipient's level of cognitive impairment affects the amount of stress experienced by the caregiver (Deimling & Bass, 1986; Rabins, Mace, & Lucas, 1982). The physical, financial, and emotional burden of elder-caregiving was studied extensively during the last decade (Anthony-Bergstone, Zarit, & Gatz, 1988; Brody, 1985; Cantor, 1983; Deimling & Bass, 1986; Gallagher, Wrabetz, Lovett, Del Maestro, & Rose, 1989; George & Gwyther, 1986; Giele, Mutschler & Orodenker, 1987; Poulshock & Deimling, 1984; Robinson, 1983; Stone, Cafferata, & Sangl, 1987; Zarit, Reever, & Bach-Peterson, 1980). Caregiver strain impairs the ability to provide eldercare and increases the risk that the care recipient will be placed in a nursing home (Chenoweth & Spencer, 1986; Colerick & George, 1986).

There is not a simple, direct relation between caregiver strain and the care recipient's level of cognitive impairment. Rather, burden peaks in the middle phases of Alzheimer's Disease when behavioral disturbances are the most profound (Pruchno & Resch, 1989). Caregiver stress is directly related to the disruptive behavior and impaired social functioning resulting from cognitive incapacity, while the degree of dementia is only indirectly related (Deimling & Bass, 1986; Haley, Brown, & Levine, 1987b). In addition, as dementia progresses during the course of Alzheimer's Disease, different aspects of the caregiver situation serve as stressors (Haley and Pardo, 1989). Consequently, the Caregiver Lesson Plans (Modules) included in this manual are organized to correspond with progressive nature of dementia. They are specifically targeted to the care recipient's level of cognitive deterioration and behavioral or social impairment.

For example, one lesson plan targeted to caregivers during the middle stages of dementia suggests ways for coping with caregiver burden. The stressful burden of caring can have dire consequences for caregivers, and eventually their care recipients. When the family collapses, so does the person being cared for (Cohen & Eisdorfer, 1986)! Caregivers must constantly balance the needs of the person with dementia with their own needs, and often with those of other members in the family.

Tenseness, anger, frustration, guilt, and sadness are normal responses to the strain of living with and caring for any individual with a prolonged or chronic illness (Cohen & Eisdorfer, 1986). The constant demands of caring can and do lead to emotional and physical fatigue. It is easy to feel overwhelmed and helpless in the situation.

Whether a stressful situation affects caregivers negatively or positively depends on how they think and feel about it, and what action they take in response to it. What is most important is not what happens to them, but how they react to it.

To manage stress, caregivers must first identify when it occurs and know their physical and emotional limits. Caregivers need relief before they exceed their limits. Respite services are one way to give caregivers a break. Respite gives caregivers time to be with friends or family and enjoy leisure activities. It also makes time for joy, calmness, and relaxation. By taking periodic breaks, caregivers can return to their responsibilities refreshed and newly prepared to deal with what's ahead.

Providing what seems like 36 hour-a-day care for a loved one whose mental, social, and physical abilities are declining is stressful. As stated earlier, the effects of Alzheimer's Disease cannot be controlled. However, caregivers **can** influence the effects of the disease on themselves.

IMPORTANCE OF SOCIAL SUPPORTS

The extent of burden reported by caregivers and their ability to cope with it, depend on the social supports available to them (Zarit et al., 1980). Caregiving assistance and support from friends and other family members can significantly decrease the primary caregiver's level of stress (Archbold, 1983; George & Gwyther, 1986; Zarit et al., 1980). Methods of intervention should focus on and involve the natural support systems of the impaired older person. Services which use the informal support network may prevent overwhelming burden on the caregiver and avoid the breakdown of the family system. Many differences in coping strategies and support systems exist among families. Some of these differences are related to cultural diversity.

IMPORTANCE OF EDUCATION

Caregivers need more information, and education will make them more effective providers. Of particular value are educational programs which improve the caregivers' coping skills, increase understanding of the recipients' psychosocial needs, encourage the use of informal and formal resources, improve the quality of relationships between caregivers and their care recipients, and explore the appropriateness of institutionalization (Smith, Smith, & Toseland, 1991). A very recent survey of family caregivers of individuals with dementia emphasized the need for more information about case management and community-based service eligibility and availability (MaloneBeach, Zarit, & Spore, 1992). A recent analysis of Alzheimer's helpline calls revealed a need for general information about dementia, home-based services, adult day care, and support group contacts (Coyne, 1991). Recognition of the societal value of family caregivers and the distress they experience has resulted in the development of a variety of education support programs (Gallagher, Lovett, & Zeiss, 1989). The project for which this manual was created builds on previous efforts but is unique in its focus on rural and minority families (see section entitled "About the Project" in the Appendix).

Among Black family caregivers there is a great need for information about Alzheimer's Disease and the availability of community resources (Segall & Wykle, 1988). Black elders receiving home care services have more limited knowledge and access to services than their White counterparts (Harel, 1986). There is some suggestion that the prevalence of dementia is higher among elderly Black community residents (Heyman, Fillenbaum, Prosnitz, & Raiford, 1991). This may be due to an increased risk of stroke because of high blood pressure. Rural Black caregivers of those with AD are particularly unlikely to seek eldercare information or services (Wood & Parham, 1990). Clearly, caregiver workshops aimed at this special population are especially needed.

Family caregivers of elders with dementia also have ethical concerns regarding: 1) the extent to which families are obligated to provide care, 2) the timing, need, and financial implications of involving professional caregivers, and 3) the patient's role in care planning (Pratt, Schmall, & Wright, 1987). These issues need to be addressed in caregiver workshops, as well. Educational intervention has helped spousal caregivers of loved ones with AD feel greater competence and be more independent (Chiverton & Caine, 1989).

When perceived burden is high, there is great risk that the caregiving subsystem will collapse. Interventions that increase the family's opportunities to receive education regarding services have been proposed to alleviate the perceived burden experienced by caregivers (Cox, Parsons, & Kimboko, 1988). The researchers found that perceived burden was unrelated to objective burden, service utilization, or stated need for services. Caregivers reported very limited use of services, but expressed a need for physical and medical assessments. Ethnic differences in utilization rates and stated need for specific services were documented. Although families expressed a need for services, they were not able to access them. Further studies focusing on the ethnic patterns of family caregiving and attention to services that address perceived burden are needed to guide policy-makers and social service workers.

Despite the need for more informed caregiving, there is some resistance to using formal educational resources, such as workshops and classes. The adult children of frail elders primarily get their caregiving skills through experience, self education, or other informal means (Manahan, 1992). Their reluctance to participate in caregiving workshops is related to past negative experiences with aging professionals and time constraints resulting from their caregiving responsibilities. Since they regard their caregiving situations as unique, they are willing to attend educational programs only when they feel that their particular needs will be addressed. (Note: The organization of this manual along the continuum of disease progression, allows caregivers to choose which workshops address their needs. They can allocate their priorities and deal with their time constraints to receive the information they most need, when they need it most.)

IMPORTANCE OF SUPPORT GROUPS

A remarkable change has occurred in the experience of families who care for persons with AD and similar memory-impairing illnesses. They have discovered each other and come together for mutual support and encouragement. Formerly, shame and isolation kept families from sharing their experiences with others. This barrier has given way to a desire for mutual support in dealing with the problems of memory impairment (Powell & Courtice, 1983). In rural communities there is more resistance to support group intervention, since social networks are more closely knit. Caregivers are initially reluctant to share their difficulties with neighbors for fear that they will become the topic of town gossip. Once trust has been established among support group members and caregivers experience the relief that comes with knowing that others have similar difficulties, resistance gives way to mutual support and encouragement.

The literature suggests that support group participation per se does not result in significant decreases in caregiver burden or depression (Haley, Brown & Levine, 1987a; Toseland, Rossiter, & Labrecque, 1989; Whitlatch, Zarit, & Von Eye, 1991; Zarit, Anthony, & Boutselis, 1987). Group support can diminish feelings of isolation, however. Sharing experiences in a supportive context can have a beneficial effect. This is especially true when it is reinforced with appropriate community services, including individual or family counseling.

The Alzheimer's Association, founded in 1979, helps people around the country establish support groups and share information. When caregivers realize that their problems are shared by other families who care for loved ones with AD, they gain a greater understanding of their own feelings. They become more able to give and receive support and strength. They gain insight which helps them improve their situations and relieve some of their burden. Caregivers also gain strength and confidence in dealing with the emotions and decisions they face (Powell & Courtice, 1983). (Note: One of the indirect goals of the current project was to increase the number of support groups in rural and African American communities. It is hoped that as caregivers come together for education, they may develop group cohesiveness and a desire to continue meeting in support of each other.)

IMPORTANCE OF FORMAL SUPPORTS

Access to community services can lessen caregiver burden and promote the efforts of families to keep persons with dementia in the community (Maslow, 1990). The need for affordable respite services and counseling to resolve major family conflicts has been documented in a study of the Black family's experience with dementia (Segall & Wykle, 1988).

Despite the need for community services, research has consistently shown that they are under-used, even when intensive levels of home care are necessary (Caserta, Lund, Wright, & Redburn, 1987; Gwyther, 1988; Lawton, Brody, & Saperstein, 1989; MaloneBeach, Zarit, & Spore, 1992; Yankelovich, Skelley, White, Clancy, Schulman, Inc., 1986). A variety of factors contribute to these low rates of service use. Often, caregivers are concerned about the ability of service providers to understand the particular needs of demented persons (Office of Technology Assessment, 1987, 1990). Ethnic and cultural variations also may influence family perceptions about the acceptability of seeking help from outside the family (Holmes, Teresi, & Homes, 1983). The tendency of Black elders to rely more on informal or familial assistance with health and financial problems has been documented (Mindel, Wright, & Starrett, 1986; Ulbrich & Warheit, 1989). Yet, older Black women have a higher risk than White elderly females of having needs unmet by primary family members (Montgomery & Hirshorn, 1991). Often, families (both Black and White) regard the use of formal services as unacceptable, preferring to be self-reliant and independent of the service system (Collins & King, 1990; Deimling, Noelker, & Chernin, 1988; Eckert & Smyth, 1988; Montgomery & Borgatta, 1989; Wilson, 1989). As will be discussed later in the manual, these values are more pronounced among rural and African American families. Although "rugged individualism" and self-reliance may be laudable attributes, these attitudes can be counter-productive for over-burdened caregivers, and can eventually result in "burn-out." Educational workshops, which modify resistance to the use of community resources and convince family caregivers to use beneficial services, can reduce the degree of caregiver stress and improve the quality of care provided.

IMPORTANCE OF POLICY

Increased education can enhance policy developers' ability to design ways or means by which they could address the existing needs of society. Chronic diseases like Alzheimer's are by definition not curable, although they are treatable and manageable. Medicare and other insurance do not pay for most of the services involved in treating chronic illness (Cohen & Eisdorfer, 1986). For those with AD, much of the care is not medical. Usually, a combination of physical and social assistance, emotional support, with occasional medical intervention is helpful. With the exception of medical intervention, such services are disallowed by Medicare (Cohen & Eisdorfer, 1986).

Medicaid is public assistance provided by federal and state governments for eligible persons, but Virginia has the most restrictive eligibility criteria allowable. The Medicaid Nursing Home Pre-Admission Screening Manual, revised in January 1993, states that home and community-based services for personal care to the person with AD are limited. Supervision is appropriate only when the recipient can never be left alone due to mental or severe physical incapacitation and there is no other family resource available to provide the needed supervision. Medicaid will not pay for nursing home placement for a person with a **sole diagnosis** of Alzheimer's Disease. This is not uncommon among the States. (Note: An indirect outcome of the current project may be to increase caregivers' self-advocacy efforts and influence public policy in support of caregiving families.)

SUMMARY

Just as the person with AD goes through a progression of stages, primary caregivers also experience various "stages," but they are not necessarily related to the care recipient's course of disease. In fact, the greatest degree of burden perceived by caregivers is related to the person's disruptive behavior and impaired social functioning rather than the degree of dementia per se. It is essential that caregivers be informed and educated, not only about the nature of Alzheimer's Disease, but also about how it affects the family. Caregivers need to be made aware of the stages that they will go through (e.g., burden, grief, etc.) as they care for their loved ones.

To this end, this train-the-trainer program was developed to provide caregiver education to rural and/or minority family members caring for a loved one with AD or a similar disorder. As studies have shown, these two populations have not been consumers of information or services in the past to the same degree as their urban and non-minority counterparts. Calling on trusted community leaders to be workshop facilitators and providing this culturally sensitive and literacy appropriate training manual constitutes one attempt to address these issues. The best training materials are useless unless delivered to responsive caregivers in a way they can benefit from it. The project is fully described in the replication plan which may be obtained from the editors (see order form in back of training manual). A synopsis is in the Appendix.

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CHAPTER 2: ETHNIC COMPETENCE FOR TRAINERS OF AFRICAN AMERICAN CAREGIVERS[2]

INTRODUCTION

An important feature of the aging American population is its increasing ethnic diversity. The overall population of ethnic elders in the four major nonWhite categories -- African Americans, Asian Americans/Pacific Islanders, Native Americans, and Hispanics -- is growing rapidly. The proportion of older adults within most ethnic groups in the United States is lower than in the general population (AARP, 1986). Yet, the numbers of older adults who are members of ethnic and racial minority groups are increasing at more than twice the rate of the overall elderly population (Gibson, 1982; Manuel, 1982; 1988). The number of ethnic elders in this country has doubled with each census since 1960, and this pattern is expected to continue well into the twenty-first century (Harper, 1990; Valle, 1988-89). This trend is influenced by the increases in life expectancy which have affected the population as a whole, and by improved socioeconomic conditions and health care for minorities. Immigration patterns are also an important factor. Among Asian Americans, for example, the Chinese and Japanese populations are aging rapidly as young adults bring their older parents to the United States in increasing numbers (Advisory Panel on Alzheimer's Disease, 1993).

The older African American population is increasing at a faster rate than the older majority, or White, population. Black elders comprise an increasingly larger proportion of the total aged population (Butler, 1989; Manuel, 1988). In 1988 there were approximately 2.5 million Blacks aged 65 years and older (U. S. Bureau of the Census, 1989). This represents over 8 percent of the total African American population. Older Blacks are the fastest growing segment of the total Black population. Between 1970 and 1980, the older Black population increased by 34 percent while the total Black population increased by only 16 percent (AARP, 1990). Projections suggest that by the year 2000 older Blacks will make up 8.5 percent of the total U. S. population aged 65 years and older. By 2040, the proportion of older Blacks in the older population will have increased to 12.5 percent.

The fastest growing segment of the older population across all ethnic and racial groups is the old-old (aged 85+). This group is increasingly comprised largely of females (Jackson & Perry, 1989; Manuel, 1988). Nearly three out of every five aged Blacks are women (AARP, 1990). Black females who survive to the age of 85 have the longest life expectancy for males or females of any racial group (Havlik & Suzman, 1987). Health professionals can expect to see increasing numbers of old-old African American females, since persons in this age group are more likely to have chronic health problems.

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[2] Joan B. Wood, Ph.D. is gratefully acknowledged as the major contributor to this chapter.

Insufficient data have been collected to provide precise information regarding incidence and prevalence of Alzheimer's Disease among ethnic and racial minority groups. However, some studies have suggested that the prevalence of dementia may be higher among older African Americans than among Caucasians (Chandra, Bharucha, & Schoenberg, 1986; Schoenberg, Anderson, & Haerer, 1985). Relatively high levels of cognitive impairment among adult African American populations have been documented (Holzer, Tischler, Leaf, & Meyers, 1984). More specifically, the prevalence rates for multi-infarct dementia are higher among African Americans than in the general population. This finding may be due to elevated levels of hypertension and other cardiovascular risk factors in this group (Baker, 1988; Folstein, Anthony, Parhad, Duffy, & Gruenberg, 1985). Elevated rates of alcohol misuse, abuse, and/or dependence across the life cycle raise the possibility of increased prevalence of alcoholic dementia among older Blacks (Baker, 1988; Viamontes & Powell, 1974). The data pertaining to cognitive impairment are paralleled by similar reports of higher rates of functional impairment. Compared with Caucasians, African Americans show a higher prevalence of deficits in activities of daily living (Leon & Lair, 1990).

Different racial groups may indeed have different patterns of dementing illness. It should be reiterated that data from population-based studies is insufficient to establish that this is the case. Adequate historical and clinical data are lacking due to problems with prior access to resources, misuse of resources, or ineffective doctor-patient relationships. These issues have also led to concerns about the accuracy of diagnosis (Baker, 1988).

ETHNICITY VS. MINORITY STATUS

In discussing the special challenges faced by Black families caring for individuals with AD, race itself is not a sufficient explanation for differences. It's important to distinguish between ethnic identity and minority status. Racial differences may result from deprivation relative to Whites (i.e., attributable to minority status). Alternatively, they may be a consequence of ethnic culture, that is, subgroup preference deriving from a unique collective history and intragroup commitment (George, 1988). Thus, minority status and ethnic identity are not the same. They can be separated into voluntary and involuntary factors. Minority status is something that a group has very little control over, because it is based on socioeconomic variables and issues related to discrimination. The role of ethnic identity, on the other hand, is very much determined by an ethnic group. Ethnic identity, in fact, derives from traditions and beliefs passed on from one generation to the next. Thus, minority status and ethnic identity may be distinguished on the basis of involuntary factors (e.g., socioeconomic variables and issues related to discrimination) and voluntary factors (e.g., cultural patterns of behavior based on culturally-based beliefs about aging, illness, or death).

It is also important to emphasize the principles of socioeconomic and cultural diversity within Black culture. African Americans include persons with common racial characteristics who can trace their roots to Africa or who were born in the Caribbean Islands (Advisory Panel on Alzheimer's Disease, 1993). There is no single "Black" culture. Education, social class, socioeconomic status, language, religion, personal experience and degree of acculturation to mainstream culture all influence individual behavior. Regionalism is also an important factor. What is generally regarded as Black culture in America, may more properly be considered part of Southern (American) culture (Gaines, 1988-1989).

DISADVANTAGED/MINORITY STATUS

The major challenge to African American families in providing care to frail elders is usually the lack of socioeconomic resources. Older Blacks are generally disadvantaged with regard to education, income, health transportation, and housing (Wan, 1977). Since the late 1970s there has been a widening gap between the poverty rates of Black and White elders (Center on Budget and Policy Priorities, 1988). The 1988 data show that 32 percent of older Blacks are below the poverty level, compared to 10 percent of older Whites and 22 percent of older Hispanics (U.S. Bureau of the Census, 1989). This disparity is particularly seen in rural areas, where nearly 50 percent of all Black elders live in poverty. More than two-thirds (68%) of rural Black women over the age of 75 are in or near poverty levels (AARP, 1986).

Older Blacks, especially rural elders, are less likely to own and drive a personal car. In rural areas where public transportation is lacking, persons without automobiles are more isolated by physical distance (Krout, 1983). This particularly affects older rural Black women, many of whom never learned to drive and are dependent on relatives and friends for transportation. The low socioeconomic status of older Blacks is compounded, therefore, with the financial and physical realities of rural living that place Black elders at a disadvantage with regard to transportation.

Eligibility criteria based on means tests discriminate against **rural elders** of all races and ethnic groups, who are more likely to own their own homes and additional property. Although rural elders may own substantial acreage, the quality of the land may be quite poor and the return on the investment very low (Groger, 1983). Older rural Blacks who have acquired property in addition to their homes are reluctant to risk their control over these or other economic resources (such as their Social Security benefits) to obtain services of questionable benefit.

Service eligibility criteria that discourage large households may also discriminate against the living patterns of Black families. The size of many minority households is determined more by economic necessity than by cultural preference. These are likely to include extended family in need of shared housing. Any number of dependent or financially independent younger individuals are likely to share the household of an older Black family member. This is the reverse of the living pattern in majority families, where the older relative is more likely to move in with an adult child or younger sibling. Older African American women are more likely than Whites to be heads of households (Jackson, 1985). However, service eligibility criteria that require the reporting of pooled household incomes may present a distorted view of the resources available to the older adult.

ACCESS TO FORMAL SERVICES

Access to formal services by racial and ethnic populations lags behind that of the majority population (Advisory Panel on Alzheimer's Disease, 1993). Several problems related to access pose special challenges to Black elders and their families. Some are related to minority status. Others are rooted in African American ethnic culture. The physical and cultural characteristics of rural living compound these difficulties. Disentangling the effects of these characteristics on access to formal services is often difficult, if not impossible.

In rural areas, where fewer services are available, elders are typically not well-informed about those services that are available (Krout, 1983; Wan, Odell, & Lewis, 1982). Older rural Blacks are particularly likely to be unaware of and not use existing services. Many public service delivery agencies, with scant resources to support existing programs, do not advertise the availability of services. When service availability is promoted, the methods used to communicate are often ineffective, and only a few respond. Older Blacks may have access to fewer channels of communication and interpretation, and are less likely to access information and referral services (Waring & Kosberg, 1980). The printed word also presents a problem for many older Blacks, who are more likely to have low literacy levels.

Long-term care services, including community-based clinical and social services, were not designed with accessibility for ethnic populations in mind. Location of services, distribution patterns, and, of course, transportation problems discourage the use of formal services by ethnic minorities. Only recently have many formal care providers begun to develop awareness of the need for cultural sensitivity in service delivery. The under-representation of minority populations in the formal care system may be primarily due to socioeconomic and systemic factors (such as poverty, absence of insurance, maldistribution of services, lack of educational opportunity). Behavior patterns reactive to the longstanding experience of having been underserved by the existing social and medical service system are also important contributors (Baker, 1980; Carlton-LaNey, 1991; Holmes, Holmes, Steinbach, Housner, & Rocheleau, 1979; Valle, 1989b). Although overtly racist practices have become legally disallowed and socially unacceptable, practices reflecting categorical stereotyping continue to exist on both an institutional and an individual level. Older Blacks who do have access to services are often offended by providers' use of their first names or other patronizing mannerisms which are seen as disrespectful.

RELIANCE ON INFORMAL CARE

The most salient characteristic of long-term care among the Black aged is the continued reliance on traditional informal supports. However, this dynamic is far more complex than the stereotypical belief that ethnic families "take care of their own." This simplistic view is largely a traditional ideal and is unsupported by research (Jackson, 1977; Jackson & Walls, 1979; Rosenthal, 1986). Ethnic culture may, however, be a resource in informal caregiving to impaired elders.

Ethnic differences in the structure and quality of informal support networks of the Black elderly have been well documented (Cantor, 1975; Conway, 1985; Jackson & Walls, 1979; Sokolovsky, 1985; Tate, 1983; Taylor, 1982; Wood & Parham, 1990). Size of the network and frequency of contact do not appear to be significant distinguishing factors. Black people seem to have a significantly broader range of informal supports, not just larger numbers of individuals willing to provide supports. Informal support systems among aged Blacks appear to generate a greater variety of, and more depth in, instrumental and emotional types of support (Sokolovsky, 1985; Wood & Parham, 1990).

Older Blacks in the rural South have reported more support from non-kin, such as neighbors and friends (Chatters, Taylor, & Jackson, 1986; Wood & Parham, 1990). The reasons for this are not readily apparent. Unique regional cultural values related to helping or regional effects of Black migration patterns may be involved (Chatters et al., 1986).

In any case, Black families seem to display a flexibility in kinship boundaries, which may have arisen from their African American heritage (Jackson & Walls, 1979; Tate, 1983; Taylor, 1982). These kinship links (often called fictive kin, i.e., unrelated persons who are regarded in terms of kinship) are based upon functional expectations and existing interpersonal relationships (Chatters et al., 1986; Tate, 1983; Taylor, 1982). Extended kin, friends, and neighbors appear to perform functions that only relatives perform in White families (Wood & Wan, 1993).

The Black church also plays a special role in the support networks of older African Americans. The church remains a significant provider of tangible services, as well as emotional and social support, in Black communities. Ministers and parishioners are often involved in providing both instrumental (task-oriented) and expressive (emotionally supportive) care on a long-term basis for frail elders (Wood & Parham, 1990).

These kinds of informal services are often seen as filling the void where formal services are not available, or when formal services are not seen as culturally appropriate. Informal transportation networks function in much the same manner. Individuals who have automobiles and the time to provide transportation services, often do so. However, such services are not always inexpensive. Often these individuals may be retirees or persons who are otherwise unemployed. Even family members may charge considerable fees for transporting frail elders to doctors' appointments or for regular shopping. Individuals who provide transportation services may support themselves financially, or enhance otherwise meager income, over many years (Wood & Wan, 1993).

While older adults, and others who have need of such services, may feel that the charges are exorbitant, they continue to use them when other choices seem unavailable. The provision of transportation and other informal services may be interpreted within the context of a system of exchange. The practice and expectation of exchanging goods and services (i.e., norms of reciprocity) are usually quite strong in Black communities. They evolved from the cooperative lifestyle that served as a survival mechanism in earlier times and continue to serve as a source of support, especially among families of low socioeconomic status

(Dilworth-Anderson, 1992). Even frail elders may provide child care, shared housing, or financial assistance to younger family members in need of aid. In return, health care and transportation services are provided to allow older individuals to live out their lives within the home and community.

INSTITUTIONALIZATION

African Americans do not use nursing homes at the same rates as non-minorities. Only 3 percent of Black elders over the age of 65 are institutionalized, in comparison with 5 percent of White elders. Among those 85 and over, only 12% of Blacks live in nursing homes or other institutional facilities, compared to 23% of Whites (AARP, 1986). Blacks have less than half (45%) the odds of Whites of nursing home admission (Greene & Ondrich, 1990). Studies based on other data have estimated that older African Americans are admitted to nursing home at between half and three-quarters of the rate of older Whites (Hing, 1989; Liu & Manton, 1989).

Because health care decision-making among minority families has been little studied, significant predictors of decisions to institutionalize Black elders are unknown. One might suppose that, as among majority families, the availability of an informal caregiver, whether family or extended kin, is likely to be the best predictor (Arling & McAuley, 1983: Palmore, 1983; Scott & Roberto, 1985). Among Black caregivers of relatives with AD, decisions to institutionalize were predicted most often by conflicts with the care recipients, while caregiver strain was not a significant determinant (Morycz, 1985). Blacks who are admitted to nursing homes are less likely to leave (Greene & Ondrich, 1990). Blacks who reside in nursing homes also tend to be somewhat more functionally impaired than Whites (Hing, 1989). These data may reflect a propensity for Black families to delay admission until resources are unable to support continued care. When informal resources are exhausted, institutional services may be sought as a last resort (Wood & Wan, 1993).

SPECIAL STRAINS FOR BLACK CAREGIVERS

Studies comparing caregivers of different racial or ethnic backgrounds have not found significant differences in the amount of strain or burden experienced by Black caregivers (Cantor, 1983; Morycz, 1985; Wood & Parham, 1990). Ethnic or cultural differences in sources of strain have not been investigated. However, some special strains and unique strengths may be rooted in the philosophical orientation of African American culture (Wood & Wan, 1993).

In Black folk medicine, diseases are seen as arising from natural, that is, physical causes. However, "natural" illnesses may also be spiritual in nature, for example, the result of sin or the willful violation of sacred beliefs (Watson, 1984). Natural illnesses may also be seen as divine punishment. The fear of illness may function as an instrument of social control (Snow, 1983). Unnatural or occult illnesses are believed to be the works of evil spirits or conjurers and reflect conflict in the social network (Davis & McGadney, 1993; Snow, 1983; Watson, 1984).

In traditional African systems of thought, the power of God is believed to be present in humans as in all other forms of matter. It is considered important, not only for one's spiritual well-being but for one's physical health as well, to live in harmony with all of nature. Good health is seen as an indication that one's life is in harmony, and disharmony is reflected in illness (Watson, 1984). African Americans, especially those from rural areas and lower socioeconomic status, who continue to be influenced by traditional folk beliefs, may conceive of illness as having a spiritual dimension. This culture-specific view of disease may be especially troubling for Black family members caring for loved ones with AD.

Anecdotal evidence supports this hypothesis (Wood, 1987). One caregiver commented to a researcher that "we have just learned to accept cancer as a physical illness. This Alzheimer's Disease is something else." Another rural Black caregiver sought the help of a "conjure woman," believing that his wife's cognitive impairment was the result of a hex or a "sign" put on her by someone who wished her harm. These folk views of illness are not mere exotic and rare occurrences. They are common among a significant number of Black Americans (Carter, 1988), especially those from the rural South (Gaines, 1988-1989). If the behaviors and symptoms of Alzheimer's Disease are interpreted in terms of a folk medical system's model of illness, medical diagnosis and treatment will likely be delayed or not sought at all, until a crisis occurs.

In Southern Black culture, much more emphasis is placed on appropriate affective relationships and on the fulfillment of role obligations than on cognitive clarity (Gaines, 1988-1989). If an elder is sometimes confused or disoriented, it may be attributed to advancing age and perhaps even considered justifiable, as retribution for past sins. Anecdotal data from neurologists and other health professionals support this hypothesis. Help is often sought for older Blacks with Alzheimer's Disease much later in the course of the disease, than is the case for older Whites.

However, the family is likely to be seriously disturbed and, because of the kinship system, many more family members are affected as the disease progresses. Multiple caregivers, in complex arrangements revolving around the job responsibilities of each, are likely to be involved. Since role performance within the family is valued, the debilitation of an older person (particularly a female with a grandchild-rearing role) can be disruptive to several family members of different generations (Gaines, 1988-1989). Awareness of the importance of affective functioning and of harmony in the African world view provides a framework for understanding that conflict with the care recipient predicts caregiver willingness to institutionalize (Morycz, 1985). Crises within support networks have been found to affect health perceptions of older Blacks, but not older Whites (Krause, 1987). The social networks of older Blacks may be a source of stress to them as well as a provider of support (Biegel, Magaziner & Baum, 1991). Emotional disturbance within one's social network or, in a family member with AD, may represent such a threat to the well-being of caregivers that they are unable to continue the caregiving relationship.

Another culture-specific source of stress may be found in the church, which is an expected source of great strength to Black caregivers. As mentioned earlier, church members and ministers are often mobilized to become an integral part of the "therapeutic/managerial community" (Janzen, 1978) which supports caregiving. When this does not happen as expected, it represents a particularly painful source of stress. This is exemplified in the instance of a caregiver who felt an especially strong sense of commitment to her church, to which she had made many contributions over the years. Dismayed that her church family did not offer to help with her husband's care, she was noted to exclaim, "If one of them would just come and sit with him one hour and let me sit in peace on my front porch ..." Her explanation for the church's failure to help her was the lack of understanding of Alzheimer's Disease. She believed that church members were afraid of the disease.

Studies of cultural differences in coping strategies employed by family caregivers of those with AD indicate some culture-specific strengths for African American caregivers. Wood and Parham (1990) reported more frequent use of prayer as a coping strategy among Black caregivers. White caregivers reported more behavioral coping strategies, such as attendance at Alzheimer's support group meetings. Black caregivers reported more use of several internal cognitive strategies for coping. These included reliance on religious belief systems and more frequent reframing of the situation in positive terms. Many of these cognitions (e.g., "I have to get through this. I've been through a lot before; I'll get through this, too") reflect determination to survive the caregiving experience.

Similarly, Black caregivers have been found to select two dominant styles of coping in caring for their confused relatives: (1) prayer and faith in God and (2) accommodating oneself to the situation (Segall & Wykle, 1988-1989). These types of coping strategies are adaptive for Alzheimer's caregivers who may be powerless to change the external and objective stressors in the caregiving situations (Wood & Wan, 1993).

Wood and Parham (1990) also found a very strong indication that Black caregivers considered God to be a part of their support system. Blacks reported the receipt of instrumental support and respite from God. This is distinct from other reported cognitive coping strategies which reflect a religious mind set and a personal conception of the divinity (Conway, 1985; Taylor, 1982; Wood & Parham, 1990). The implication of this finding supports a culturally-based distinction between a religious belief and a personal relationship. From the perspective of Black caregivers, God is perceived in a very personal way and is considered as much a part of the informal support system as family, friends, or neighbors (Wood & Parham, 1990).

TIPS FOR TRAINERS OF AFRICAN AMERICAN CAREGIVERS

1) Be aware of the diversity among African American families. While we have noted several distinctive characteristics (e.g., patterns of caregiving, definition of family, definition and use of social supports, unique stressors, cultural strengths), we must be mindful of categorical stereotyping. Each family caregiving situation is different.

2) Because older rural Blacks typically do not use available services for a variety of reasons, your role as a trained advocate is particularly important. Your assistance as a translator, facilitator, and/or escort may be needed. You may need to identify service providers and help direct caregivers to them. You may even need to go with them to assist in negotiating the formal service delivery system.

3) An alternative strategy for encouraging utilization of needed services is to provide information about the services to younger members of the community. They may be less timid in dealing with formal service providers.

4) The Black church may serve as a powerful medium to provide information and educational services, not only to primary family caregivers, but to others who are likely to become part of the caregiving community for parishioners with AD.

5) Although Black caregivers seem to be more adept at utilizing complex informal support systems than do Whites, it is important to remind them that we need to allow others to help us. One of the most important lessons of caregiving is that we must take care of ourselves first, in order to be able to provide care to others.

6) Caregivers should be encouraged to seek appropriate medical evaluation of relatives who are suspected of having Alzheimer's Disease or related disorders. Even if the efficacy of medical interventions is limited, that does not mean that "nothing can be done." It is very important to obtain an accurate diagnosis rather than ignore a situation that is potentially reversible.

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CHAPTER 3: SPECIAL CONSIDERATIONS FOR TRAINERS OF RURAL CAREGIVERS[3]

Note: See Addendum for the latest descriptive statistics from the Centers for Disease Control and Prevention, National Center for Health Statistics (Van Nostrand, 1993).

INTRODUCTION AND DEFINITIONS

The most prominent characteristic of rural America is its social and economic diversity. Across the nation, and even within rural communities, residents differ widely in terms of their economic resources and social status. The information presented here provides a summary of the rural elderly and their family caregivers, with a focus on those dealing with Alzheimer's Disease and other dementias. This chapter describes the rural elderly as a group using general terms, and contrasts them with older people in urban areas. It is important to remember, however, that the families you will encounter as a trainer may differ in terms of their beliefs, values, customs, histories, traditions, and health practices. Residents within a single rural community differ from each other, and different rural areas may be quite distinct. **Trainers should offer help on the caregivers' own terms and address what the caregivers feel are the important problems. Respect their approach to working with their loved ones.** The supports and services offered in urban areas may not be the most appropriate for rural caregivers. For example, the urban emphasis on biomedical technology, specialists, and referrals may seem alien, uncaring, and unsympathetic to rural families (Longino & Smith, 1993).

People in rural Appalachia, and American Indians and African Americans in rural areas, still practice popular or folk medicine. Folk "healers" trust and rely on poultices, tinctures, teas, and herbs. Trainers who recognize, rather than ridicule, these practices are more likely to be effective in recruiting and educating rural caregivers. Some folk remedies (ginseng, foxglove, yellow root, and others) have real medicinal value (Lewis, Messner & McDowell, 1985). Physicians (and others) from outside rural communities can improve rapport with residents by condoning the safe practice of folk medicine (Lang, Thompson, Summers, & Hood, 1988).

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Prayer, spiritual healing, and laying on of hands are also considered effective treatment by some. There is a tendency to use religion when coping with adversity and depression, especially among poor, African American elders (Rosen, 1982). As mentioned in the previous Chapter, prayer and a reliance on spiritual guidance is a coping method used by many rural, African American family caregivers of elders with Alzheimer's Disease (Wood & Parham, 1990). **Trainers should value and respect the religious beliefs of caregiving families, and avoid contradicting or belittling them.**

It is important to keep in mind the view that the rural elderly have of themselves. The rural elderly often do not see their lives or circumstances as particularly problematic. Just the opposite may be true in some cases. Surveys have found that rural elders have high morale and are satisfied with their lives (e.g., Krout, 1986). Although incomes are lower in rural areas, the elderly residents of these communities do not think their financial situations are particularly different from others (Goudy & Dobson, 1985).

Practicality, efficiency, work, friendliness, honesty, patriotism, deep religious commitment, social conservatism, and a mistrust of government are common values and attitudes in rural areas (Krout, 1986). The idea that government and voluntary agencies should provide for the welfare of a community is contrary to the more-widely held values of independence and self-sufficiency (Kaiser, 1987). Rural elders may view supportive social services and health care programs with suspicion and contempt (Harbert & Wilkinson, 1979). Many rural elders (and their family caregivers) believe that they should handle all their problems themselves. Accepting any assistance means admitting that they are weak and have failed (Smith & Buckwalter, in press). This fierce and independent spirit will challenge the trainer recruiting rural family caregivers. Families need to understand that education will make them better caregivers and allow them to shoulder the caregiving burden longer. **Trainers should emphasize the strengths of families and compliment them on the caregiving skills they already have. Let them know that your intention is to help them be more independent by enabling them to keep their loved ones at home and delay nursing home placement.**

Attendance at the workshop may involve the principle of reciprocity, i.e. families may feel the need to reciprocate for the education provided by offering food or other gifts. Although trainers should explain that this is not necessary, families may insist. It is better to accept graciously than to refuse and offend the giver. If trainers refuse token gifts, caregivers may feel that they are in the position of accepting charity and refuse further assistance (Wentowski, 1981). **Gaining a clear understanding and healthy respect for the traditions and practices of rural family caregivers is critical to successful outreach to rural families. This knowledge and attitude will help trainers successfully offer much valuable information to help rural families provide better care for their loved ones with dementia.**

Everyone has some notion of what a rural area is. For some it is a small town; to others it is farm country; and some think of the vast plains of the Midwest. There are really two ways to talk about differences between those who live in the city and those who live in the country. The "urban" populace are those living in an urbanized area. That is, those living in an incorporated place and surrounding area with at least 50,000 residents, or a place where 25,000 or more people live. The term "rural" refers to the residual; it is the population which lives elsewhere (Clifford, Heaton, Voss, & Fuguitt, 1985).[4] The term "non-metropolitan" designates counties without any towns that have 50,000 or more residents. There is some overlap between these two different ways of classifying populations.[5]

WHO ARE THE RURAL ELDERLY?

Both urban and rural dwellers often believe that country living and family life is simple, pure, wholesome, slow-paced, relaxed, and serene (Coward & Smith, 1982). Studies of the differences between the rural and urban elderly suggest that in many ways the rural elderly may be at a severe disadvantage.

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[4] The National Rural Strategy Conference in 1978 recommended to the Administration on Aging a definition which states that in order to be considered rural, one of the two following criteria must be met (Ambrosius, 1981):

1) For a county or a set of counties comprising a Standard Metropolitan Statistical Area (SMSA), as defined by the U.S. Bureau of the Census, the rural areas comprise all open country, unincorporated areas, and incorporated areas (villages, towns, cities) of less than 25,000 total population except those areas in places of 10,000 or more total population which are adjacent to, contiguous with, or part of the suburban fringe (urbanized area) of a city of 50,000 or more total population.

2) For all counties (non-SMSA) the rural areas comprise all open country, unincorporated areas, and incorporated places (villages, towns, and cities) of less than 25,000 total population (p. 294).

[5] Just over half (54%) of the rural population lives in non-metropolitan areas. About two-thirds (66%) of the non-metropolitan population is rural, and 16 percent of the metropolitan population is rural (Rogers, 1993).

A larger proportion of the population in non-metropolitan areas is elderly (Rogers, Goldstein, & Cooley, 1993). The concentration of elderly in non-metropolitan areas has increased in the last decade as retirees "moved in" and young adults "moved out." Older adults in rural communities tend to "age in place" (Krout, 1986), that is, they stay where they are and grow older. The rural elderly are more likely to be married and not widowed (Dwyer, Lee, & Coward, 1990), especially those who live on farms (Krout, 1986). Rural elders tend to have more children (Clifford et al., 1985), and are less likely to be childless (Lee, Dwyer, & Coward, 1990). This is primarily a cohort effect as progeny were regarded as labor resources for farm families. The existence of larger families in rural areas does not mean that adult children are available and willing to provide care for them, however. Rural elders who do not live on farms are particularly unlikely to have children who live near by (see Stoller & Lee, 1993 and Lee & Cassidy, 1985 for reviews of the literature). Rural residents, especially farmers, continue to work at ages when many others have retired. When they do retire, it is usually for health reasons. In general, fewer of the elderly residents in rural communities are minorities (Goldstein & Rogers, 1993). Elderly African American persons in nonmetropolitan areas tend to be poorer than those in metropolitan areas. The rural elderly tend to be more impoverished and less educated (Lingg, Braden, Goldstein, & Cooley, 1993). Nonmetropolitan elders are more likely to have dropped out of high school and less likely to have attended college.

Trainers who have not worked in rural areas may encounter these rural-urban lifestyle differences for the first time. It is important not to pass judgments simply because families may have fewer economic resources. A lack of wealth does not necessarily translate into a lack of status in rural communities. Particularly among rural Blacks, status in the community is often conferred on the basis of factors unrelated to financial situation, and community leaders are not always those with higher incomes. It is equally important not to make assumptions, since each family's circumstances will be different. Trainers should be aware of the differences that do exist. **Structure your approach and training content in a way that is immediately appropriate and useful to the family caregivers you encounter. Trainers should also become familiar with the particular communities in which their family caregivers reside. Try to find out as much as your can about the "way of life" or the social mores ("dos" and "don'ts") operating in the localities you target.** This will allow you to offer useful and relevant instruction and advice to your caregivers.

The next section of this Chapter discusses rural/urban differences in housing, health status, health services usage/expenses, minority health status, and mental health. This information should help you become more knowledgeable about the difficulties faced by rural elders and their families.

Housing. The majority (60%) of the nation's substandard and dilapidated housing is in rural areas (Krout, 1986), and rural elders occupy a disproportionate share of those homes (Byland, 1985). Many lack hot water and indoor plumbing. Although their homes are of lower value (and in poorer condition), the nonmetropolitan elderly are more likely to own their own homes. They are also more likely to own them "free and clear," i.e., without a mortgage (McGough, 1993). Nonmetropolitan elders tend to make cash purchases, or to arrange for shorter mortgage terms when financing is used. The comparative lack of adequate housing for elders in rural areas may be due in part to rural-urban differences in education and income. Several other factors may also contribute to the problem. There are fewer housing programs for the elderly in rural areas (Lawton, Hoover, & Kostelc, 1978; Taietz & Milton, 1979). On the other hand, many rural elders who live in substandard housing will not accept any governmental assistance to improve their homes (Montgomery, Stubbs, & Day, 1980).

Health status.[6] Since the rural elderly have more severe health problems, they end up retiring for health reasons (Youmans, 1963, 1974). A larger proportion of the elderly in non-metropolitan areas describe their own health as either fair or poor (Van Nostrand, Furner, Brunelle, & Cohen, 1993). In addition, the rural elderly are more likely to suffer from various medical conditions (Coward, 1988; Palmore, 1983; Youmans, 1967), chronic illnesses (Dahlstein & Shank, 1979; Paringer, Bluck, Feder, & Holahan, 1979), and disabilities (Palmore, 1983). Older adults in rural areas are more likely than those in urban areas to have difficulties with activities of daily living (ADLs), like bathing and eating, or instrumental activities of daily living (IADLs), like shopping and doing housework (Coward & Cutler, 1988; Cutler & Coward, 1988; Krout, 1989a). The rural elderly may also be more limited in their activities because of illness (Cutler & Coward, 1988; Krout, 1986; Paringer et al., 1979; Youmans, 1967, 1974).[7]

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[6] Although the information presented is an attempt to characterize the health status of rural elderly based on the available literature, these conclusions should be interpreted cautiously. Kivett (1985) advises against the use of generalizations since other factors (such as proximity to metropolitan locations & utilization of urban health services) tend to minimize rural-urban differences in some localities. Krout (1986, 1989) also warns that differences in research methods and definitions of "rural" make it difficult to draw firm conclusions in the absence of more careful, systematic studies.

[7] Some data suggest otherwise, however. A recent comparison of non-metropolitan and metropolitan elderly failed to reveal any differences in the percentage of those who experienced impairment in one or more ADL or IADL (Braden & Van Nostrand, 1993). There were also no differences in the proportion of metropolitan and non-

One comprehensive review of the literature comparing the health status of rural and urban elders concludes that: "No matter what measurement of health status is used - self-assessment by the elderly individual of health as excellent, fair, or poor; reports of ailments; reports of mobility limitations; use of health aids or prescription drugs; number of days hospitalized; or any combination of these - the results are always the same: the rural elderly are in relatively poor health" (Ecosometrics, 1981, p. 94).

Health services usage and expenses. On the average, rural elders spend less on health care than older adults in metropolitan areas (Kovar, 1984). The use of medical services in rural areas increased dramatically when Medicare and Medicaid programs began (Harris & Cole, 1980; Roemer, 1976). The fee for enrolling in Medicare Part B (physician services) is generally lower for rural residents. Although this encourages rural participation, it also decreases reimbursement rates and hospital payments. Elders in non-metropolitan areas are less likely to have private insurance coverage to supplement Medicare coverage (Braden & Cooley, 1993). This exclusive reliance on Medicare may be due to a misconception among rural elders that Medicare insurance "covers everything." The net effect is increased out-of-pocket expenses for health care among the rural elderly. On the other hand, a slightly greater proportion of rural elders are covered by both Medicare and Medicaid. This may be partly due to the greater levels of poverty in rural areas, and the increased need for home health services that are covered by Medicaid, but not Medicare. Many poorer, rural states either choose not to participate in Medicaid, or have very low levels of reimbursement. This eliminates the possibility of Medicaid coverage for elders in non-participant states, and makes the rural-urban difference in Medicaid coverage smaller than what it might be otherwise. The lower levels of reimbursement may cause doctors, hospitals, and nursing homes in rural areas to be more reluctant to accept Medicaid patients.[8]

Minority health status. This topic was discussed in the previous Chapter. In this context it should be noted that older African Americans living in rural and

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metropolitan elders who limited their activities because of illness, i.e., both groups reported about 31 restricted activity days and 14 days of bed rest per year on the average (Van Nostrand et al., 1993). Although statistically significant differences were not found, the proportion of non-metropolitan elderly experiencing impairment was in fact greater than the proportion of metropolitan elderly who were impaired.

[8] Rural-urban differences in Medicare and Medicaid expenditures are more obvious among elders with functional disabilities. The average percentage of expenses paid for by Medicaid is higher for impaired elders in non-metropolitan areas, while the proportion paid by Medicare is lower (Braden & Cooley, 1993).

non-metropolitan areas are sicker than those in urban areas. Rural, nonWhite ethnic groups (especially African American males) are much more likely to experience chronic illness (McCoy & Brown, 1978). Non-metropolitan, African American elders are much more likely to rate their health as fair or poor than either their metropolitan counterparts, or non-metropolitan White elders (Van Nostrand et al., 1993).

Mental health. It is difficult to say that the incidence of mental illness is greater among the rural elderly.[9] Approximately 15-25 percent of those over the age of 65 suffer from mental illness or emotional distress (Buckwalter, Smith, & Caston, 1993). The rural and urban elderly are probably not different with respect to the kinds of psychiatric disorders they experience (Buckwalter, et al., 1993). Rural elders are not as frequently seen by mental health professionals in ambulatory settings, however. Metropolitan residents have about twice as many visits to mental health professionals as non-metropolitan residents, and are more likely to see a psychiatrist or psychologist (Taube, Kessler, & Freurberg, 1984). In general it appears that community mental health services are under-utilized, especially among the elderly (National Institute of Mental Health, 1981). The rural elderly account for only a small percentage of community mental health center clients nationally, and less than 7 percent of the caseload of private psychiatrists (Kermis, 1986). One often cited study found that only 1 percent of small-town elders had received formal mental health services, while the number "at risk" was between 12 percent and 23 percent (Scheidt & Windley, 1982).

DEMENTIA AND CAREGIVING IN RURAL AREAS

There is very little information documenting the incidence of dementia among the elderly in rural areas. The incidence of dementia in non-metropolitan areas is probably the same as in metropolitan areas. It is likely that dementia is under-diagnosed in rural areas, however, since specialized diagnostic and evaluative services are not as readily available. Rural family caregivers of elders with Alzheimer's Disease may be less likely to seek out information about their problems (Wood & Parham, 1990). Rural/urban differences among family caregivers of elders with dementia are important considerations for trainers when employing outreach and education strategies in rural areas.

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[9] Some studies report more mental illness in urban areas, others report the opposite finding, and still others find no difference (see Scheidt, 1985 for a review of the literature). National studies comparing the rural and urban elderly provide the best information. One national study (Schooler, 1975) found that the rural elderly were significantly more alienated and had lower morale. Another (Campbell, Converse, & Rodgers, 1976) showed that the rural elderly were happier, had greater community satisfaction, and less fear of crime.

Many older persons do not know what is normal and abnormal when it comes to the mental and emotional aspects of aging. They sometimes fail to realize that the memory losses they experience during the early stages of Alzheimer's Disease are not a part of "normal" aging. In that instance, trainers can help family caregivers distinguish between normal and abnormal aging processes. Encourage caregivers to share that information with the elders they care for, and direct them to professionals for thorough diagnostic tests if warranted. Although Alzheimer's Disease has a physical basis, there are a number of psychosocial and psychological changes associated with the cognitive decline which characterizes dementia. Counseling and/or therapy may be very appropriate and quite helpful in dealing with the mental health aspects of dementia and caregiving.

NEED FOR MENTAL HEALTH SERVICES

The Chair of the former House Select Committee on Aging, Edward R. Roybal, has argued eloquently for much needed reform in the mental health care system for the elderly (Roybal, 1988). The problems of limited access, a lack of trained professionals in geriatric mental health, lack of outreach, and inadequate benefits are even more severe and more consequential to isolated rural elders (see Wagenfeld, 1990 for a 10-year review of the literature documenting urban-rural differences in access, availability, staffing, and quality of mental health services). Recent federal initiatives (such as changes in reimbursement for outpatient mental health services, efforts to improve mental health services at community health centers through the Bureau of Health Care Delivery and Assistance, and Department of Agriculture mandates to establish linkages between state extension services and state mental health programs) may improve the delivery of mental health services in rural areas (Wallace & Colsher, 1993). In addition, training programs that emphasize practice in rural areas may aid efforts to recruit mental health professionals (Hargrove, 1991). Meanwhile, the need for community treatment among non-institutionalized elderly residents in rural areas persists. Most of the elderly who receive mental health services are in nursing homes. It has been suggested that older adults in rural areas may be inappropriately placed in nursing homes because of the lack of available alternative mental health care (Intermill & Rathbone-McCuan, 1991). Elders who reside in the community make up 95 percent of those age 65 or older, but receive only 1.3 percent of the federal money for mental health services (Kermis, 1986). Many rural elders have only limited access to mental health services. Only 7 percent of rural counties have a general hospital with psychiatric facilities (Flax, Wagenfeld, Ivens, & Weiss, 1979). As a consequence, rural residents must rely on general practitioners who may be reluctant or unable to accurately diagnose and treat geropsychiatric problems (German, Shapiro, Skinner, Von Korff, Klein, Turner, Teitelbaum, Burke, & Burns, 1987; Gurland & Cross, 1982; Linn, Gurel, Williford, Overall, Gurland, Laughlin, & Barchiesi, 1985; Waxman & Carner, 1984). Very often when mental health care is provided, it comes from nurses, social workers, and others without advanced training in the delivery of mental health services (Jones & Parlour, 1985). One statewide survey in Virginia found that 23.2 percent of elders who were treated for mental health problems, received these services from a member of the clergy (MacAuley, Arling, Nutty, & Bowling, 1980). Without the diagnostic, medication, and consultation services provided by psychiatrists and psychologists, however, third party reimbursement becomes difficult, if not impossible. Where mental health services are regionally structured, they are either available only in satellite offices, or their availability in communities is restricted and infrequent (Buckwalter et al., 1993). Community mental health centers in rural areas have more difficulty recruiting and retaining mental health professionals than those in urban areas (Stuve, Beeson, & Hartig, 1989). Many do not offer any specialized service for the elderly. In addition, many rural residents either have negative attitudes toward community mental health centers, or little knowledge about what agencies have to offer. The emphasis is often on rehabilitation and outpatient services which generate income, while community education and consultation services are neglected (Zevenbergen & Buckwalter, 1991). Yet, this information could help change attitudes about mental illness, improve early recognition and treatment, and reduce the risk of institutionalization and long-term disability. This is especially critical when complex legal and ethical issues are involved, such as determination of competency and balancing the safety and autonomy needs of persons with dementia.

Cultural beliefs and the stigma attached to mental illness may be the most important barriers to the use of mental health services in rural areas. Mental problems are regarded as private family difficulties, and those who turn to scientific medicine may be thought "desperate" (Hill, 1985). Accepting mental health assistance may be seen as a sign of personal weakness and tantamount to defeat (Smith & Buckwalter, in press). The "fear of stigma is so strong among some of the [rural] elderly that they never reach out for assistance" (Rathbone-McCuan & Hashimi, 1982, p. 102). Many elders fear being labeled as "crazy" and believe they will be abandoned or "locked up" if they accept mental health assistance. They wrongly believe that mental illness is still treated by putting people in state mental hospitals or asylums. For the rural elder who values freedom and independence, institutionalization looms as a "fate worse than death." Their families are afraid that when neighbors and friends find out about their older relatives with mental problems, "they will become the topic of town gossip, the brunt of bad jokes, and will be avoided, shunned, or ostracized" (Buckwalter, Smith, & Caston, 1993, p. 281).

To counter the stigma and cultural beliefs which impede the utilization of mental health services, trainers should gain insight into why these fears and misconceptions exist. They should be aware of widely-held values which affect how the rural elderly and their families deal with mental health problems. Rural values are grounded in notions such as fatalism, subjugation to nature, and fierce individualism, which can all work against the acceptance of formal assistance. For example, the "spirit of independence" may decrease the likelihood that mental health problems are recognized and perceived as psychological difficulties (Coward, 1979). Trainers should recognize that the values of rural elders are "post figurative." That is, they are passed down from older to younger persons. There is an emphasis on cultural stability, gradual change, and a belief that norms and practices will endure (Ansello, 1981). **In addition, a clear understanding of the stressors, coping strategies, and goals of family caregivers is critical to effective education.** The rural elderly are not a homogenous group (Harbert & Ginsberg, 1990), and there is much diversity within rural communities. Differences in values and beliefs must be thoroughly investigated and not simply assumed. **Trainers are advised to immerse themselves in the "cultural milieu," and find out how the workshops they plan to offer fit into the communities they have targeted (Bischoff, 1976). To borrow from urban terminology, trainers should become "streetwise" and gain some insight into the social practices of the communities where their family caregiver trainees reside.**

NEED FOR COMMUNITY-BASED SERVICES

Rural elders and their families are less likely to be using formal community-based services than those in other areas (Blieszner, McAuley, Newhouse, & Mancini, 1987). One major goal of the workshop training should be to encourage family caregivers to use community services more fully. Various localities will differ markedly in the resources that are available. **Trainers should make a concerted effort to find out exactly what is offered in the particular area they have targeted. This preparation is important if families are to be fully informed about how to get the assistance they need.** The sections which follow describe the kinds of agencies which may be able to offer assistance to rural families. Particular attention is given to how these services are delivered in rural areas and the problems associated with access.

Area Agencies on Aging. The best source of information about the community resources available in any particular area is the Area Agency on Aging (AAA, pronounced triple-A). These agencies develop, coordinate, and provide a wide range of community-based services for the elderly. They are particularly important in rural areas because of the general lack of available services. To compensate, rural AAAs provide almost twice as many direct services as urban AAAs (Krout, 1991). Yet, the number of different kinds of services provided by rural AAAs is more limited (Krout, 1991; Nelson, 1980, 1983; Taietz & Milton, 1979). Fewer AAAs in rural areas offer in-home services and adult day care. Rural AAAs typically have smaller budgets and staff, since funding is based on numbers, and they serve fewer clients. Since they cover larger territories, more of their funds are devoted to transportation. About half the states in this country use an intrastate funding formula that is weighted to include a rural factor. This helps provide a more equitable distribution of state funds. The significance of this weighting factor is often quite small, however (Krout, 1991, 1993).

Even when community based services are available, they are under-utilized by rural elders because they are not accessible (Bull, Howard, & Bane, 1991). Geographic isolation, poor roads, and the lack of any public transportation often prevent elders from receiving any formal services. Although distance is a major reason services are inaccessible, other factors (e.g., lack of knowledge about service availability, client eligibility restrictions, and administrative practices) are also barriers (Ecosometrics, 1981). Recognizing that rural elders are often not aware of the community-based services available to them, most rural AAAs offer information and referral. Even so, there are persistent obstacles unique to rural areas (such as poor telephone communication systems, larger service areas requiring toll calls, and homes without telephones). These all prevent widespread knowledge about service availability (Coward & Rathbone-McCuan, 1985). Despite all of the difficulties, rural AAAs have been resourceful and continue to develop creative programs to overcome these barriers (see Krout, 1989b for examples).

Home Health Services. Home health care refers to health services provided in the homes of the elderly. The delivery of home health services eliminates the transportation difficulties faced by consumers. The accessibility issue then becomes an obstacle for the agency that has to go into the community to deliver home-based services. Ironically, rural elders who are functionally impaired do not use home health services as much as their urban counterparts (Braden & Van Nostrand, 1993). It also appears that home health use among Medicare enrollees may be considerably lower in rural areas (Beaulieu, 1993). Home health care is vitally important to families with elders in the middle and late stages of dementia. This service can allow families to keep their loved ones at home for a longer time and delay nursing home placement.

Senior centers. Although senior centers primarily provide socialization and recreation, they often provide information and referral, and may offer specialized services. Senior centers are frequently used by rural AAAs as service delivery sites. They sometimes are a key link between rural elders and the larger aging services network (Krout, 1993). Most rural senior centers offer health screening and education, congregate and in-home meals, and nutrition education. Less than one-third offer homemaker or home health care, however, and less than 10 percent offer on-site adult day care (Krout, 1983b). Rural elders are more likely to attend senior centers than those who live in urban areas (Krout, Cutler, & Coward, 1990). Rural senior center clientele tend to be older, poorer, and more frail than those who attend urban senior centers (Krout, 1993). Rural senior centers have lower budgets, smaller staff, smaller facilities, fewer activities and services, and fewer linkages with other community agencies (Krout, 1983, 1989b). During the last decade while urban senior centers expanded, most rural centers remained essentially unchanged, further widening the gap between urban and rural resources (Krout, 1989b, 1993). Although older adults who attend rural centers are in greater need of assistance (especially support programs such as SSI, food stamps, heating assistance, etc.), they are less likely to get help because budgets are so limited.

Adult day care. Adult day care programs offer support and relief for family caregivers by providing care for functionally impaired elders. There are approximately 2,100 such programs in the U.S., and most of these have come into being during the last decade (Heide & Webb, 1991). Despite the advantages offered by these programs, some caregivers are reluctant to place their loved ones in adult day care. They may feel that others will not provide the same quality of care and concern. They may also harbor a basic distrust of service providers, or they may be reluctant to let others "take over" what they feel is their exclusive responsibility and duty. Anecdotal evidence suggests that this resistance may be especially strong among rural caregivers (Krout, 1989b). In addition, adult day programs are not particularly accessible to rural caregivers. Approximately one-third of the AAAs in rural areas do not offer any adult day care programs, or the programs are located some distance away (Krout, 1989b). Funding for these programs is often a problem in rural areas, as are some state regulations requiring the attendant services of health professionals (Krout, 1993). The programs in non-metropolitan areas are less likely to provide clinical services (such as physical, speech, occupational therapy), care planning, counseling, personal care, or therapeutic recreation (Krout, 1993). They have fewer clients, shorter waiting lists, and lower client-to-staff ratios. Adult day care is an important mechanism by which family members can get much needed respite from their caregiving responsibilities. Although some adult day care centers do not take older clients with AD, many are well-equipped to handle the special problems associated with dementia. While some persons with AD may be initially opposed to spending time away from their homes and familiar caregivers, others look forward to their "visits" with excited anticipation. **Where adult day care services are available, trainers should urge caregivers to give serious consideration to this option and encourage them to try it.**

Case management. Case management generally involves some form of systematic planning, coordination, and service delivery for individuals at-risk of institutionalization. The intention is to help disabled elders and their families get the "best mix" of available services. It is designed to help elders remain in the community and avoid early entry into nursing homes. Case management has become a core component in most community-based, long-term care programs (Austin, 1992), and is available to some extent in much of rural America (Krout, 1989b). Financial constraints, transportation difficulties, and the general lack of available and accessible services make the provision of this service particularly problematic in rural areas (Beaulieu & Hickman, 1992; Krout, 1993; Parker, Quinn, Viehl, McKinley, Polich, Detzner, Hartwell, & Korn, 1992). Although it is harder for rural agencies to meet case management guidelines, rural case managers tend to have more contact with their clients (Krout, 1993). The network of informal caregivers for rural elders may be stronger, and there are more opportunities to work with local volunteer groups in the provision of services (Beaulieu, 1993). The Carle Clinic Association in Champaign-Urbana, Illinois provides a model case management program targeted to rural residents with AD and their families as part of the Medicare Alzheimer's Disease Demonstration (Schraeder, Shelton, Dworak, & Fraser, 1993). This program demonstrates the benefits of using case management to compensate for many problems associated with a fragmented system of community-based services in rural areas. There are distinct advantages to providing family care and direct service to caregivers, while maximizing the usefulness of informal support systems already in place.

Privately-paid hired help. Hiring help is an option available to rural elders who can afford it and can help compensate for the lack of accessible formal services. Yet, many rural elders and their family caregivers are reluctant to spend their savings on housekeeping, yard work, or personal care services (Parker, Quinn, Viehl, McKinley, Hartwell, Van Hook, & Detzner, 1992). At the same time, traditional rural values limit the kinds of favors one can comfortably ask of others as a kindness or courtesy (Stoller & Lee, 1993). By paying a neighbor to do menial tasks, rural elders and their families can maintain a sense of independence (Shenk, 1987). Private-paid help allows older adults with dementia and their family caregivers to minimize the need for assistance from friends and relatives, and in some sense, control their own caregiving situation. When adult day care is not a suitable means of obtaining respite services, this alternative can be "just what the doctor ordered." Unfortunately, finding individuals who are trained in the care of persons with dementia and willing to independently contract to provide services, may be difficult in rural areas. **Trainers should emphasize the importance of finding a sitter who is congenial, and either knowledgeable, or willing to learn about the care recipient's condition.** In the special case of caring for someone with AD, considerable instruction may be necessary. Once an appropriate substitute caregiver is found, however, the respite relief provided may be worth far more than the expense and effort involved.

NEED FOR HEALTH SERVICES

Access and availability of health services. There are fewer health services available to rural elders (Coward & Cutler, 1989; Krout, 1986, 1993; Taietz & Milton, 1979). The unavailability of services can be traced historically to inequitable differences in the distribution of funds (Kivett & Learner, 1981; New York State Senate Research Service, 1980; Parkinson, 1981). In 1981 for example, one fourth of the Medicare dollars went to rural areas where two-thirds of the Medicare recipients lived (Kim, 1981). Considerable improvements in the number and kinds of services available to rural elders have occurred over the last decade. Even so, there are still substantial differences between the rural and urban health and human service networks (Christianson & Grogan, 1990; Hicks, 1990; Krout, 1991). There are fewer physicians, nurses, and other providers of health care in rural settings (Conway-Welch, 1991; Hicks, 1990; Hicks & Glenn, 1991; National Rural Health Association, 1992; Wright & Jablonowski, 1987). In 1988, there were 176 rural counties in the United States that did not have a single primary care physician (Taylor, Puskin, Cooley, & Braden, 1993). About 30 percent of rural Americans live in federally-designated, primary care physician shortage areas (Bureau of Health Professions, 1990). Older adults in rural areas usually have to travel greater distances to receive outpatient treatment, and they have to wait longer for services once they arrive at the site of care (Taylor et al., 1993). Registered nurses are also under-represented in rural communities ("Facts about nurses," 1987), and this shortage is particularly acute in long term care settings (i.e., nursing homes). In an attempt to compensate for the shortage of physicians, efforts have been made to increase the supply of nurse practitioners and physician assistants in rural areas. Although this strategy had some initial success, there is currently a movement away from practice in rural areas. For example, less than 20 percent of physician assistants practice in communities with less than 10,000 people (Hicks, 1990). The situation is even more acute with respect to nurse practitioners.

Institutional Long Term Care. Little is known about rural-urban differences in institutional long term care. Nursing home services in rural settings may be even more important than ambulatory services due to the relatively larger numbers of elderly. In rural communities, the dominant providers of long-term care are nursing homes (Shaughnessy, 1993). Many rural communities that do not have hospitals do have chronic care nursing homes. In 1990, slightly more than 40 percent of all Medicare- or Medicaid-certified nursing homes in the country were in non-metropolitan areas (Shaughnessy, 1993). The number of nursing homes per capita is higher in non-metropolitan areas. Although metropolitan nursing homes have more beds on the average, the bed-to-elderly ratio is substantially higher in rural areas. Since hospitals tend to discharge patients as soon as possible, intermediate care in nursing homes may be convenient if their residences are some distance away from the hospital (Coward, McLaughlin, Duncan, & Bull, 1993).

There is some concern that rural elders may enter nursing homes prematurely (Greene, 1984). Some have suggested that rural elders are being "over-institutionalized" (Shaughnessy, 1993). If this is the case, the lack of accessible community home care and medical treatment may be to blame. The problem may be particularly serious for older rural women who have outlived their husbands and have more trouble managing transportation and medical costs than do older rural men (Krauss, Spasoff, Beattie, Holdern, Lawson, & Rodenburg, 1976).

Since many persons with AD eventually need nursing home care, rural caregivers must give careful consideration to appropriate placement. The quality of care in rural facilities may be better than that in urban institutions (Kart & Manard, 1976). Anecdotal data suggest that the staff in rural nursing homes are more attentive to the functional and support needs of residents (Shaughnessy, 1993). This may be due to a greater familiarity between nursing home staff and the family and friends of nursing home residents in smaller, close-knit rural communities. There may also be lower turnover rate among staff in rural nursing homes. Sometimes however, nursing home residents may be "over-provided" assistance with ADLs and IADLs, when they should be encouraged to function more independently. It is important to remember that there is considerable diversity in terms of the quality of long-term care services provided in rural nursing homes. Overall it seems that chronic care services are adequate in these facilities, although rehabilitation services may be lacking (Shaughnessy, Schlenker, & Kramer, 1990). If nursing homes are evaluated thoroughly and selected carefully, there is no reason why placement needs to be made in an urban facility that is far away.

Policy Considerations. Recognizing the disparity between the health care available to those in rural and urban communities, the federal government established Area Health Education Centers (AHECs) and the National Health Service Corps. AHECs were established in the 1970s to train and support local health care practitioners. This initiative has succeeded in increasing the primary care physician-to-population ratios in counties where they have been set up (Hynes & Givner, 1990). Except for these programs, the national policy has been tied to the free-market approach. The expectation is that health care providers will relocate to rural areas when the supply in urban areas has been saturated (Hicks, 1990). There is also the assumption that rural communities would provide economic incentives for health providers to relocate, if the need were great enough. This assumption ignores the fact that many rural communities have an inadequate economic base for tax revenues to establish such incentives (Ossofsky, 1978). Another widely held misconception is that the resistance to using formal services among the rural elderly accounts for differences in health services utilization in rural and urban areas. This argument fails to countenance other relevant factors, such as availability, access, cost, quality, and knowledge of services.

Currently, it does not appear that there are significant differences in hospital admission rates or inpatient treatment for rural versus urban Medicare beneficiaries (Taylor et al, 1993). The disproportionate number of rural hospital closures in recent years (Bernstein, Kolimaga, & Neuschler, 1988) threatens to exacerbate the access difficulties which already exist, however. The construction of hospitals in rural areas over the last 50 years, through the federally funded Hill-Burton program, was a demonstration of the nation's commitment to improving access to health services. Rural hospitals came to have a central role in the lives of rural residents, often defining the nature of rural communities. A community's ability to recruit and retain physicians is enhanced by the presence of a rural hospital (Crandall, Dwyer, & Duncan, 1990). In recent years the noble goal of improving health services access has been all but forsaken in favor of cost considerations, competition, and market forces. Consequently, the hospitals which remain have been forced to reduce services and are less responsive to the needs of the community. The implications of this policy shift could seriously compromise the health of rural elders (see Duncan, 1993 for a discussion of policy alternatives and approaches to dealing with the attendant economic problems).

INFORMAL CARE

Much of the care for older persons living in community settings comes from informal helpers, such as family, friends, and neighbors. Informal services (i.e., services provided by family, friends and neighbors) comprise most of the support for the elderly. Indeed, the development of educational and support programs to help family caregivers cope with their caregiving responsibilities should be an essential ingredient in any national plan to contain health care costs. The rural elderly may be more likely than their urban counterparts to rely exclusively or primarily on informal helping networks (Arling & McAuley, 1984; Blieszner, McAuley, Newhouse, & Mancini, 1987; Coward & Dwyer, 1991), and less likely to use paid helpers (Dwyer & Miller, 1990b). This difference is especially true among elders with greater levels of impairment.[10]

This greater reliance on informal support is due, in part, to the inaccessibility or unavailability of formal services in rural communities (Deimling & Huber, 1981; Krout, 1986). Other barriers to using formal supports (e.g., the failure to perceive a need for services, negative attitudes about receiving outside assistance, fears associated with the loss of independence, and a lack of understanding about bureaucratic procedures) are important factors contributing to this tendency to rely on informal support networks (Scott & Roberto, 1985).

The aging network has long recognized the essential role played by informal caregivers in rural areas (Newhouse & McAuley, 1987), and the centrality of the informal helping network as the primary source of aid and assistance to rural elders. Over the last ten years, serious attention has been focused on cultivating and enhancing the resources available to caregivers. (Note: The federally-funded project which produced this training manual, is a prime example of the national effort to better meet the needs of the elderly by supporting their family caregivers.) Formal service providers in rural areas are challenged with the need to coordinate the provision of both formal and informal care to maximize the benefits of each. Considerable skill is required to assure that potential conflicts between the goals and perspectives of formal and informal caregivers are either minimized or avoided altogether (Nieto, Coward, & Horsley, 1989). **By approaching family caregivers with an offer to supplement rather than supplant their caregiving responsibilities, trainers can show families how available community services can be intertwined with their caregiving efforts. In this way, families can provide more effective care for a longer time.**

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[10] Among a national sample of elders impaired in nine or more ADLs or IADLs, those in non-metropolitan areas "were more apt to continue to rely on a helping network comprised entirely of informal helpers" (Coward, Cutler, & Mullens, 1990, p. 47). In fact, three out of every four received help only from informal sources.

The norm of reciprocity is an important consideration to keep in mind when encouraging family caregivers to use formal supports. Although exchanging favors is the "neighborly" thing to do, the inability to reciprocate can be demoralizing and negatively affect self-esteem. When matters of personal care are involved, older rural women prefer the assistance of formal service providers. This help can be accepted "without a feeling of loss of independence or becoming a burden as would be the case in depending on a relative or friend" (Shenk, 1987, p. 17). **Trainers should explain that using formal services can minimize the need to depend on family and friends and reduce the stress associated with violating the norm of reciprocity by relying too much on others.**

The tendency to use informal supports does not necessarily mean that there are stronger kinship ties across generations in rural areas. While the traditional rural values of familial obligation and filial responsibility would suggest a greater degree of interaction between elderly persons and their children (Deimling & Huber, 1981; Heller, 1970, 1976; Lee, 1980), this may not be the case (Krout, 1988). Residential proximity (i.e., geographic distance) is an important determinant of the extent to which adult children interact and provide care to their aging parents in rural areas (Adams, 1968; Krout, 1988; Lee, 1980; Litwak & Kulis, 1987).

Existing research does not support "the stereotype of the super-supportive rural informal network or the picture of the isolated rural elderly. The rural elderly would appear to have interaction and support patterns with children, other kin, and friends and neighbors not widely different from the elderly who reside in other places" (Krout 1986, p.137). "If the rural elderly really were uniquely advantaged by embededness in strong, supportive kin networks, in contrast to the 'isolated nuclear families' of the urban elderly (see Lee, 1980), their needs for public services might indeed be less. The fact is that they are not" (Lee & Cassidy, 1985, p. 165).

Although informal helpers in rural areas provide higher levels of care with fewer outside supports, they should not be expected to bear any more responsibility than those in urban areas (Biegel & Maguire, 1982; Coward, 1982). No one should assume that fewer resources need to be devoted to the problems of the rural elderly, or that the need for supportive public services is less (Goode, 1963; Krout, 1988). Furthermore, the existence of stronger or larger informal support networks does not necessarily reduce the levels of stress and burden experienced by rural caregivers. To the contrary, the relation between care recipients' levels of impairment and caregivers' burden is even stronger among rural families (Dwyer & Miller, 1990a, 1990b).

CONCLUSION

Trainers need to recognize the importance of informal networks when educating family caregivers. They must respect and enhance the rural values of self-reliance and independence. Trainers can help family members understand the older person's need to be as autonomous as possible throughout the course of dementing illness. Training in basic home nursing skills will simultaneously improve the quality of care provided and increase the caregiver's sense of competence and mastery. By teaching families about the course of Alzheimer's Disease and other dementias, families will know what to expect and how to deal with the problems which arise. Adult children must learn to provide care while also "allowing (their parents) to remain in control . . . and without appearing to usurp (their) responsibilities" to the extent that this is possible (Mercier & Powers, 1984, p. 174). Given the prevalence of gender-based stereotypes and the adherence to traditional sex roles among rural couples (Stoller & Lee, 1993), care-giving wives may need to learn how to set limits on their duties. When the care recipient is the wife, husbands must be gently coaxed into becoming proficient at tasks normally designated as "women's work."

Since many rural families prefer to manage care themselves, there may be resistance to the notion of case management. While this strategy may counter the fragmentation of services in rural communities, the reluctance to be "drawn into an all-encompassing system of social services" (Shenk, 1987, p. 23) may be an over-riding concern. Trusted community members (physicians, clergy, pharmacists, & mail carriers) can assume some of the information and referral responsibilities of rural case managers. They can serve as an "important link between the formal and informal (care) systems that are available" (Shenk, 1987, p. 25). Trainers should acknowledge and build on the strengths that naturally occur in rural communities. Networking and resource-sharing with churches and other community organizations can enhance volunteer efforts to identify and help rural family caregivers.

There are five major factors to consider when developing and delivering services to the rural elderly. "(They) include the existence of a large diversity within and between rural communities, the existence of a considerable age diversity within the rural elderly, the need to recognize that there are many myths about the rural elderly (such as super-strong extended family ties) that must be discarded, the need to establish ties with existing community units, and the importance of including the elderly's 'significant others' in the service delivery process" (Krout, 1986, p.156).

TIPS FOR TRAINERS OF RURAL CAREGIVERS

1) Offer help on the caregivers' own terms and address what the caregivers feel are the important problems. Respect their approach to working with their loved ones.

2) Value and respect the religious beliefs of caregiving families, and avoid contradicting or belittling them.

3) Emphasize the strengths of families and compliment them on the caregiving skills they already have. Let them know that your intention is to help them be more independent by enabling them to keep their loved ones at home and delay nursing home placement.

4) Gain a clear understanding and healthy respect for the traditions and practices of rural family caregivers. This knowledge and attitude will help you offer much valuable information to help rural families provide better care for their loved ones with dementia.

5) Structure your approach and training content in a way that is immediately appropriate and useful to the family caregivers you encounter. Become familiar with the particular communities in which the family caregivers reside. Try to find out as much as you can about the "way of life" or the social mores ("dos" and "don'ts") operating in the localities you target.

6) In order to counter the stigma and cultural beliefs which prevent the use of mental health services, try to gain insight into why these fears and misconceptions exist. Try to get a clear understanding of the stressors, coping strategies, and goals of family caregivers.

7) Immerse yourself in the "cultural milieu," and find out how the workshops you plan to offer fit into the targeted communities. To borrow from urban terminology, you should become "streetwise" and gain some insight into the social practices of the communities where the family caregivers reside.

8) Make a concerted effort to find out exactly what kinds of services are available in the community you have targeted. This preparation is important if you are to instruct families on how to get the assistance they need.

9) Urge caregivers to give serious consideration to respite care options and encourage them to try it. Emphasize the importance of finding a sitter who is congenial, and either knowledgeable or willing to learn about the care recipient's condition.

10) By approaching caregivers with an offer to supplement rather than supplant their caregiving responsibilities, families can be shown how available community services can be intertwined with their caregiving efforts. In this way, more effective care can be provided for a longer time.

11) Explain that using formal services can minimize the need to depend on family and friends and reduce the stress associated with violating the norm of reciprocity by relying too much on others.

12) Recognize the importance of informal networks when educating family caregivers. Respect and enhance the rural values of self-reliance and independence. Help family members understand the older person's need to be as autonomous as possible throughout the course of dementing illness.

ADDENDUM

The following information is based on data from the Centers for Disease Control and Prevention, National Center for Health Statistics (Van Nostrand, 1993).

In 1989, 22 percent (54.6 million) of the U.S. population was non-metropolitan and 27 percent (66.2 million) was rural. About 15 percent (8.2 million) of those in non-metropolitan areas are elderly, while only 12 percent (23 million) of the metropolitan population is elderly. About 26 percent of all citizens age 65 or older live in non-metropolitan areas.[11]

Ninety-two percent of non-metropolitan elderly are White persons compared to 88 percent of older adults in metropolitan areas. Elderly African American persons in non-metropolitan areas are more likely to be poor than their metropolitan counterparts. Nearly one-half of elderly African American men (45%) and women (48%) had incomes below the poverty level in 1990. In metropolitan areas the poverty rates were 22 percent and 35 percent for elderly Black men and women, respectively.

Only 18 percent of non-metropolitan elderly were in high-income families, compared with 27 percent of metropolitan elderly, and their monthly Social Security benefits are about $60 less on the average.[12] In 1987, one-half of the non-metropolitan elderly had incomes below 200 percent of the poverty level, while only 37 percent of metropolitan elders had incomes in this range. Non-metropolitan elders are more likely to have dropped out of high school and less likely to have attended college. Data from the U.S. Census Bureau (1991) indicates that a greater proportion of non-metropolitan elderly completed less than nine years of school (one-third versus one-fourth). Only about 10 percent of older adults in non-metropolitan areas have completed four or more years of college, compared to about 13 percent of metropolitan elders.

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[11] There has been some suggestion that the South has an exceptional number of older adults living in rural areas. For example, Beaulieu (1993) cited data indicating that the two areas of the United States having the largest concentrations of rural elderly are the South, with 32.7 percent of the elderly living in rural areas, and the Midwest, with 29.6 percent living in rural areas. Recent census data, however, shows that although the South contains the largest share of both non-metropolitan counties and non-metropolitan population, the proportion of elderly persons in the non-metropolitan South is not substantially greater than in other regions of the country (Rogers, 1993).

[12] Benefits averaged $539 for persons in non-metropolitan areas, compared with $599 for those in metropolitan areas. Among men, benefits for non-metropolitan residents averaged $637, compared with $711 for metropolitan residents. Average benefits for women were $470 and $526, respectively.

In 1989, elderly households in non-metropolitan areas were 70 percent more likely to have moderate to severe problems with maintenance, plumbing, or kitchen equipment. The median value of elders' homes in non-metropolitan areas is 62 percent of the value of elderly-owned houses in metropolitan areas. This is partly due to the fact that elderly-owned homes in non-metropolitan areas are relatively older (19% were built before 1920, compared to only 11% of those owned by elders in metropolitan areas).

The per capita supply of primary care physicians in non-metropolitan areas ranged from 56 percent of the metropolitan supply in the South to 72 percent in the West. Physician-to-population ratios were related to county size, with the smallest non-metropolitan counties having one-quarter as many physicians per capita as the largest counties. The non-metropolitan elderly were almost twice as likely to travel more than 30 minutes to reach health services (13% versus 7%), and more than 20 percent of them have to wait longer than 30 minutes at the site of care once they have arrived.

More than one-third (35%) of the metropolitan elderly with at least one ADL or IADL impairment received at least one home health care visit during 1987, while only 27 percent of their non-metropolitan counterparts received this type of care.

The average annual medical expenditures for metropolitan elders without ADL limitations was $3,415, compared with $2,865 for non-metropolitan elders. Expenditures among elders with ADL impairments were higher for metropolitan elders however ($12,169), than for non-metropolitan elders ($7,100). The use of health insurance is approximately equal among metropolitan and non-metropolitan elders without ADL limitations. Comparisons between elders with ADL impairments however, indicates that the average percentage of expenses paid for by Medicaid was higher for non-metropolitan elders (13% versus 8%) while the proportion paid by Medicare was lower (30% versus 36%).

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CHAPTER 4: HOW ADULTS LEARN[13]

You tell me and I forget
You teach me and I remember
You **involve** me and I learn.

- Ben Franklin

INTRODUCTION: PASSIVE VS. ACTIVE LEARNING

In grade school you were expected to memorize everything the teacher said. Then you were graded based on how much information you could "regurgitate" back on a written test. Although memorization is an important ingredient in learning, it is the lowest level of learning. The theoretical framework of education described is called "pedagogy," literally, the art and science of teaching children. While pedagogy is appropriate for teaching children and learning specific tasks or basic information, andragogy is the preferred method or theory in teaching adults. Adult educators and researchers have learned that adults prefer an instructor or trainer to facilitate learning, rather than simply deliver information. Andragogy focuses on the characteristics of adults and how they learn.

GENERALIZATIONS ABOUT ADULT LEARNERS

Most mature adults are independent and self-directed. Adults determine what they need to know and how they are going to learn a new skill or subject. Autonomy is important to adult learners because they are accustomed to being their own boss or being responsible for themselves. Some adults, however, may lack self-confidence based on past learning experiences and need reassurance of their ability to learn.

Adult learners bring their life experience to learning situations. Adults bring extensive background experience from both their personal and professional lives. The older the adult learner, the more wisdom and life experience may be contributed or drawn from in a learning environment. A trainer should use the learners' experiences as major resources to help adults relate their experiences to the topics being studied. This is one reason it is helpful to open a learning situation with an ice breaker. A "getting acquainted" exercise allows the trainer and the learners to understand where the group is coming from. This background information can be integrated into the new learning experience by the trainer.

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[13] Debra Young Barbuto is gratefully acknowledged as the major contributor to this chapter.

Adult learners are problem-centered. Adults need to know why they need to learn something before they will take the time to learn. No one likes to waste time. The adult learner must value an instructional event in order to learn new information.

Adults want to be treated and respected as adults. No one likes to be talked down to in any learning situation. Adult learners want to contribute and participate in decision making processes. Throughout the learning experience, encourage feedback about the pace of the course, learners' understanding of key concepts, the relevancy of information, and other pertinent issues.

NATURE OF LEARNING FOR THE ADULT

- Adults can diagnose their own needs.
- Adults must want to learn.
- Adults will learn only what they feel the need to learn.
- Adults learn by doing.
- Adult learning centers on problems, and the problems must be realistic.
- Experience affects adult learning.
- Adults learn best in an informal environment.
- A variety of methods should be used in teaching adults.
- Adults can evaluate their own progress toward learning goals.

LET'S GET PHYSICAL!

The physical environment of a learning experience can deter or enhance learning. Trainers need to consider the learners' basic needs, anticipate potential learning slumps, choose appropriate training sites, and insure that room arrangements are optimal for productive learning experiences.

Basic Needs. If adult learners are drowsy, hungry, thirsty, or fidgety, their primal needs may be overriding their learning abilities. It's as if their bodies are saying, "Take care of me first! Then, I can learn." Allow short breaks every 30-45 minutes. People may need to move around to increase blood circulation, get some fresh air, refuel their bodies with food and drinks, or use the restroom. Short breaks allow the instructor and the adult learners to recharge their systems to engage in more effective learning.

Potential Slumps. Three of the most challenging time periods, or slumps, to teach and learn in are the early morning, after lunch, and at the end of the day or program. The early bird may get the worm, but the night owls (i.e., those who are not "morning people") may not be fully alert during an early morning learning session. The after lunch slump is challenging, because many people feel drowsy after filling their stomachs. Drowsiness is a natural physical response to meeting the body's food energy needs. The end-of-the-day slump combines several factors including: 1) mental "burn out" from information overload, 2) physical exhaustion from the day's activities, and 3) anticipation attacks, otherwise known as, "Get me out of here so I can run errands, prepare a meal, go to the bank, etc." Try to plan interactive training methods (i.e., small group work, discussions, role plays) for these potentially sluggish time periods of the day.

Locating the Facility. Try to remember the first few days of entering high school or college. One of your first objectives was to locate the room where a special subject or course was taught. If you couldn't find the classroom before the bell rang or the instructor began, your blood pressure started rising. You cursed whoever designed the map, and once you found the room, you threw yourself into any available seat (usually in the front row), and "died" of relief, embarrassment or exhaustion. This type of experience is called frustration, and when an adult learner becomes frustrated from an experience such as this, their learning abilities diminish greatly until their bodies return to equilibrium or a safety zone. It's important, from a program planning standpoint, to ensure that the location where the training will take place is clearly defined from the building to the room. Signs can be posted to direct people to rooms and through the hallways, or key personnel stationed at strategic check points can guide and welcome participants.

Parking Spaces. Parking is also an important factor to consider when planning a program. Ensuring that parking is available on or near the site is important. The parking spaces should also ensure safety and be well lit for evening programs. Participants want to feel safe going to and from an activity. The feeling of security enhances their ability to learn once they are in the program.

Handicapped Accessibility. The facility where the program will be held should be handicapped accessible for disabled adult learners. Ramps should be available if stairs are present. Hand railings are helpful, especially on stairs. Bathrooms and water fountains should be accessible for wheelchairs and people using walking devices. Doorways should be wide enough for wheelchairs to pass through. Hallways should be well-lighted for diminished eyesight, commonly associated with aging. Elevators, if available, should also be wheelchair accessible with slower closing doors to allow more time for loading on and off the elevator.

Atmosphere Affects Learning. The **decor** of a room can affect learning in a negative or positive way. If the room appears dark and dreary, the participants may feel depressed. When energy levels slow because of a somber mood, learning abilities decrease. In contrast, a bright, more cheerful room promotes higher energy levels and increases an adult's learning capabilities. If learners are extremely hot or cold due to **room temperature**, they are more likely to remember the physical discomfort than the new learning material. Although you can't please everyone, strive for group consensus about a comfortable room temperature. Often thermostats are not within the trainer's control. It's important to check a room before the training session. If needed, contact the appropriate personnel (custodians, maintenance people, etc.) to adjust the room temperature accordingly. **Proper lighting** enables adult learners to learn more effectively. For older adults, incandescent or yellow lights are more comfortable than the glaring fluorescent lights found in most facilities. Beginning around age 45, people generally require more light to see clearly. Older adults also experience more glare problems. It's important for a trainer to be sensitive and choose a training site with proper lighting.

Murphy's Law for Trainers

If anything can possibly go wrong, it will.

Therefore, stay calm, try to be flexible,
and use large doses of humor.

Room Set-Up. Adult learners prefer relaxed settings to learn in. Sitting in rows facing the instructor is generally associated with childhood learning experiences. There are several alternate room set-ups more appropriate for adult learners.

1) Clusters of 5-6 chairs around several tables in the room are ideal for small group activities.
2) If the group is small (12 participants or less) everyone, including the trainer, could sit around a conference table.
3) If chairs in rows are necessary due to a large group, have the participants move up to the front rows (since they are generally empty). Pulling everyone in closer to the trainer encourages cohesion among the group.

Under no circumstances should the instructor hide behind a podium or table throughout the entire learning experience. A podium may be used occasionally to stress key points of information. Otherwise it conveys strong non-verbal messages of the trainer's superiority and authority over the group. In some cases it may relate the trainer's underlying insecurities and fears about leading a group. A confident, relaxed instructor moves freely around the room and is accessible to the learners.

> Each person learns at an individual pace, according to his or her own degree of understanding.
>
> - J.E. Kemp

CHARACTERISTICS OF SPECIAL GROUPS OF LEARNERS

Identifying Learner Characteristics. Are you training a group of IBM executives or caregivers of African American and rural elders with dementia? It is important to understand the characteristics of the group of people you are training in order to meet their learning needs. Before you meet the participants, think about who they are and where they are coming from. How old are they? Are they males or females? What is their economic status, ethnic background, education level, or occupation? All of these questions help formulate a general idea about these adult learners' life experiences. Analyzing the audience also helps you communicate with them more effectively. Don't make the mistake of assuming that all the caregivers will be similar and should be treated the same. Remember that each individual's experiences and needs are different!

Ethnic Minority Learners. One training difficulty may stem from language barriers created by local dialect. It may be helpful to familiarize yourself with the dialect when training in an unfamiliar setting (i.e., town, county, etc.). Cultural and social differences should be recognized because they can affect the learner's ability to take responsibility for individualized work or participate in group activities. Suggestions to help ethnic groups build confidence in their ability to succeed include:

1) creating cooperative activities because many minority learners gain satisfaction from group projects and from assisting others;
2) providing culturally relevant and varied examples as illustrations of key points of new information;
3) allowing more time for study and for completion of assignments and more opportunity to practice a skill if needed; and
4) utilizing more visual aids than verbal explanations of key concepts and information.

It's important to find out as much as you can about the learning abilities of ethnic participants prior to the training. Information can be obtained from educators, counselors, ministers, librarians, and others within the ethnic community. Be careful not to make assumptions based on ethnic stereotypes. There is a great deal of diversity within various minority groups, and within communities.

OLDER ADULT LEARNERS

There are several concerns related to the special characteristics of older adult learners which should be considered. Medications, visual abilities, and hearing impairments can cause difficulties for older adult learners.

Medications. Medication, especially multiple medications, may affect the ability to learn by altering alertness, speech, vision, memory, physical coordination, and thinking processes. Generally, medications slow down these sensory, psychomotor, and mental skills.

Visual Abilities. The term, "presbyopia," refers to vision changes that are associated with aging. Changes may occur in visual acuity, farsightedness, nearsightedness, focusing ability, depth perception, peripheral vision, glare resistance, dark adaptation, and color vision. In some older adults, blindness may occur from glaucoma, cataracts, diabetes, or complications with blood circulation. Some persons, however, maintain perfect vision into old age. There are several important factors to remember concerning an older adult's vision.

1) older adults should not be expected to focus on objects at varying distances.
2) older adults' peripheral vision may shrink and limit their ability to detect objects outside the vision field.
3) with aging, it takes longer to adjust to darkness or sudden lighting changes.
4) color vision tends to fade, with red fading the least.
5) it becomes more difficult to distinguish among blues, greens and violets.

To compensate for these factors, the trainer should consider:

1) using large, well-spaced lettering for printed materials;
2) allowing a longer amount of time to view visual materials, such as slides and charts;
3) using high contrasting colors in written materials and visual aids;
4) designing large visual aids;
5) combining verbal reinforcements with visual information;
6) controlling glare from various types of lighting;
7) monitoring the participants to detect anyone experiencing visual difficulties; and
8) planning seating arrangements to accommodate limited peripheral vision.

Hearing Impairments. The term, "presbycusis," refers to a reduction in the ability to hear sounds, especially at higher frequencies, which is associated with aging. Hearing impairment has various causes, and several problematic consequences. When a person has difficulty hearing, he must rely on other skills for communicating. Generally, when people cannot hear very well, they concentrate much harder on a speaker's face and lips to attempt to understand the message being conveyed. Hearing loss makes a person feel isolated in the noisy blur around them. It is not unusual for an older adult to feel angry and paranoid as a result of this sensory loss. There are several factors to keep in mind concerning hearing loss.

1) hearing changes affect approximately one in four people 60 years or older.

2) hearing impaired persons may hear many sounds, but may not be able to understand what is being said.
3) trainers who speak too rapidly will cause understanding to be diminished.
4) words sounding alike (e.g., cheese, please, tease, sees) may cause some confusion.
5) background noises greatly interfere with the ability to hear and understand a speaker.
6) microphones may cause hearing problems for people with hearing aids.

To compensate for these conditions, the trainer should consider:

1) speaking clearly, but without exaggerated enunciation;
2) talking in a loud low tone of voice;
3) slowing down the pace of the training;
4) facing the learners as directly as possible when speaking;
5) rephrasing key points for understanding and reinforcement;
6) controlling background noises by closing doors or windows;
7) carefully explaining new words and terms; and
8) watching facial expressions and body language of the participants to detect hearing problems.

Learning Credo

- Learning is a life-long process.
- Learning is linked to motivation.
- Learning is an active process, not a passive one.
- Learning materials must be appropriate.
- Learning takes time.
- Learning needs to be interesting.
- Learning needs to be reinforced.
- Learning needs to be assessed.
- Learning rates are different.

TRAINING METHODS

Ideally, a trainer should mix various training techniques within an adult learning experience to provide the richest opportunities for learning. By utilizing various techniques, the trainer also stimulates learners' senses and greatly enhances learning. There are several common, practical methods for training small and medium sized groups that trainers should consider.

Group Discussion Using Dyads and Triads. Group discussion involves an exchange of information among two or more participants. Break the training group into dyads (two people per group) and triads (three people per group) to discuss an issue or problem that the learners are studying. If your entire group has 12-20 participants, larger sub-groups of 4-6 adults can be formed instead of dyads and triads. Small group discussions allow each participant to interact and contribute to the learning experience. They also enable adults to open up and feel more comfortable sharing their experiences and ideas. Give the groups 15-20 minutes to discuss the assignment, then have each group share their ideas with the larger group as the trainer facilitates. For example, the instructor would say, "Sherry, could you report the findings of your group." This type of exercise is ideal to use with questionnaires or written materials too. After the learners complete the written assignment, the trainer could say, "Pair up with the person next to you and take 15 minutes to discuss questions 1,2,5,6 and 8." Then the instructor would have each diad report to the entire group, reemphasizing key points, pulling together the main ideas of the assignment, and facilitating in other ways. Consider having participants pair up with different partners throughout the training for different discussions to increase group interactions.

> Learning is not a spectator sport.
>
> - Anonymous

Role-playing. Role playing provides participation, involvement, and action learning. It allows the acting out (experiencing) of real-life situations in a safe environment. The "actors" and the audience learn from the performance and can discuss ways of improving a situation or potential problem. This type of exercise also elicits feelings from the "actors" and the observers creating empathy and increasing sensitivity to a situation or a particular group of people. Role playing brings out creativity. It stimulates all the senses and is a very informal, relaxed method of learning. Everyone is affected in some way from this type of experience. Once again, the trainer acts as facilitator encouraging participants to describe their feelings, reactions, impressions of the role play; emphasizing key points or objectives to learn from the experience; and summing up the activity.

Handouts. Handouts provide participants with information that they can read, discuss as a group, reflect upon, and keep for their own future reference. Handouts may include articles from journals, newspapers, or other written material. One type of handout is an outline or agenda for the course or learning experience. This acts as a guide for the learner to follow. Handouts which emphasize key points, definitions of new terms, or concepts can also be created and distributed to the learners. Handouts which include graphs, charts, or pictures can convey complicated information in a simple, concise format. Providing reading lists on the topic(s) being discussed can inspire further learning beyond the training experience. An annotated bibliography or brief verbal review of the list can help motivate learners to pursue outside reading. When using handouts the trainer is providing tools to stimulate the learner's visual skills and thinking processes. Reference lists should be included on handouts which combine information from several different sources. Make sure the handouts are clearly readable and not poor "copies made from copies that were made from copies."

Using Visual Aids. When using visual aids ask yourself some key questions.

1) Will everyone be able to see them from where they are sitting?
2) Will the visuals emphasize the most important points?
3) Is the information in each visual clear and concise?
4) Are the visual aids appealing?
5) Are they in good condition for presenting?
6) Does each visual convey one main idea?

Flip charts can be made ahead of time and used as needed throughout the training session. They can be used to summarize discussion points, present facts, give instructions, initiate activities, to list brainstorming ideas, etc. **Overhead transparencies** are inexpensive and easy to create and use. Like handouts, they can be used to illustrate ideas, summarize points, and present cartoons or graphics. They can be pre-made or created during the training session. The overhead projector needs to work properly. Make sure that everyone can see the projection screen. It's a good idea to have extra bulbs on hand in case one burns out during your presentation.

You cannot teach a man anything. You can only
help him discover it within himself.

- Galileo Galilei (1564-1642)
Italian astronomer and physicist

The Lecture. The lecture is the most commonly used, and overused, technique. In a lecture format the trainer or speaker talks and the learners hopefully listen. Generally, a question and answer period follows at the end of the presentation. This method works well with any size group, but is widely used for large groups. It's an easy way to present a large amount of information in a short amount of time. Unfortunately, not all trainers/speakers were born with a natural, professional speaking talent. If a speaker is boring the audience, those in attendance are probably not learning or retaining very much information. This method also creates the illusion that the speaker is an expert or authority on a subject, which may or may not be true. This approach is formal and limits an adult learner's participation level in learning. When combined with other training methods (video tapes, experiential exercises, etc.), however, the lecture provides adults with a variety of learning experiences while efficiently communicating new ideas, challenges, concepts and other information in a stimulating and informative way.

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CHAPTER 5: RECRUITMENT OF CAREGIVERS AND CONDUCTING WORKSHOPS[14]

IDENTIFYING AND RECRUITING CAREGIVER TRAINEES

Some trainers may already know African American and rural family caregivers and can encourage them to participate in the workshops they conduct. Others have strong ties with the community and can network through those ties to find caregiver trainees. For example, at the end of this Chapter are announcements to be inserted in church bulletins. Trainers should consider contacting church leaders and asking if they could arrange for the inserts to be placed in their bulletins. Two separate versions have been developed. One insert is targeted toward African American caregivers and one is targeted to rural caregivers. Copies can be made by you or the churches you contact. Through the use of these inserts, family caregivers will become aware of the workshops to be offered and other church members can be asked to "spread the word." **Networking or word-of-mouth advertising may be the single best method for recruiting caregiver trainees.**

Also at the end of this Chapter is a sample press release to aid in the recruitment of caregivers. Local newspapers are often willing to publicize the activities of projects which provide assistance to the residents of their communities.

Trainers should develop a list of potential caregiver contact or access resource people who will help them recruit caregivers. Individuals affiliated with community service agencies and organizations that serve persons with AD and their families are good candidates. The advantage of working with these contacts is that caregivers are more likely to participate if the workshop is promoted by someone they trust.

Establishing a good rapport with the contact persons is very important. The best way to achieve this rapport is by meeting with them personally. These meetings are critically important. The contact person must be assured that you are qualified to be a trainer, i.e., that you: 1) have some knowledge of the training content (Alzheimer's Disease, caregiver issues, etc.); 2) can effectively facilitate groups and communicate information to others; and 3) have strong ties in the community or experience working with caregivers. Don't feel embarrassed about "blowing your own horn." Your contacts will have more confidence about recommending your workshop if they are aware of your outstanding abilities. In addition, the best trainers will demonstrate leadership and problem-solving abilities. Good interpersonal skills, patience, and sensitivity to the special needs of African American and/or rural caregivers are also valuable attributes. Finally trainers need to be flexible and able to adjust to the needs of caregivers.

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[14] Maxcine Maxfield is acknowledged for her contribution to the sections on Building Trust and Unintentional Abuse and Neglect.

Prior approval from the referring agency head may be needed. Agency personnel who serve as caregiver contacts may want to get clearance from their agency or organization before calling caregivers. Contact persons, then, must get permission from the potential caregiver trainees before releasing their names to trainers. **Because of their commitment to keeping information about their clients confidential, most agencies and organizations will insist that the initial contact with family caregivers come from them**. The agency will call or write to the caregivers to explain the benefits of participating in the project, encourage their involvement, and obtain either oral or written permission allowing the agency to release their names to the trainer.

Once you get a referral, you will need to call the caregiver to arrange for participation in the workshop. It is helpful if you can get a little background information about the caregivers before you call them. Caregivers will be more likely to participate if they feel that you are interested in them personally. The more you know about their caregiving circumstances, the easier it will be to provide the "personal touch."

CONTACTING CAREGIVERS AND ASKING THEM TO BECOME TRAINEES

When you call caregivers to obtain their commitment to attend the workshops, follow each of the steps listed below.

1. Review any information that you may have been given by the referring agency concerning the caregivers and their care recipients.
2. Introduce yourself clearly and briefly mention how you came to be a trainer (for example, identify your place of employment if it relates to the proposed workshops).
3. Explain how you obtained the name of the caregiver, and name the referring agency.
4. Describe the goals of the workshop series. In particular explain that the workshops are:

a. targeted to African American and/or rural family caregivers of elders with Alzheimer's Disease and other dementias;
b. designed to help families provide better care for their loved ones;
c. intended to strengthen caregiving families by providing information about available community resources and services; and
d. conducted to improve caregivers' knowledge about Alzheimer's Disease and other dementias.

5. Discuss how their participation in the workshops would be beneficial. Because caregivers don't have a lot of available time, they must be convinced that it will be worth the special efforts that they must make to find free time. Specifically mention that:

a. they are not alone; other caregivers can benefit from their experiences and vice versa;
b. there are distinct advantages to learning about community resources and services that exist to support caregivers and help them provide better care;
c. they will learn various tips and techniques which will make them better able to provide care for their loved ones;
d. the workshops should help them deal with any frustrations or problems they may be experiencing; and
e. they will learn how to be more effective in managing their time and balancing their other responsibilities.

Note: As you are explaining the goals and benefits of the workshops, be sure to allow the caregivers to make comments or ask any questions that may occur to them.

6. Tell them how many workshops will be offered and how long each one will last. Make sure they understand that each one is different, and that you are not offering a choice of times for the same content. Let them know that the workshops will be organized according to the progression of dementia so that caregivers can get the information they need when they need it. The first workshop(s) will deal with issues that are important when a person is first diagnosed or is beginning to first experience symptoms of dementia. The subsequent workshop(s) will cover issues that arise later on in the illness, and the last workshop(s) will concern topics that occur during the end stages.

Impress upon caregivers the importance of attending all workshops, since the information provided will be useful, regardless of their particular situation.

7. Be sure to let them know that the workshops are being provided for free. Be prepared to work with them to facilitate their involvement. If there are problems related to transportation or paying someone to sit with their care recipients, let them know that you are willing to work with them to find a way for them to attend. Be considerate of caregivers' needs. It is difficult enough for them to find the time to attend the workshops. Respite and transportation should not be additional obstacles. If assistance is needed, caregivers may be asked to consider using community services (adult day care or companion care, if it is available). Alternatively, caregivers may know someone they want to sit with their care recipient. It is best if trainers can arrange to reimburse caregivers for respite and transportation expenses. Carpooling may also be a feasible solution to transportation difficulties. Some community agencies may be willing to provide a few introductory respite visits in order to attract more regular clientele. Be resourceful! Don't be afraid to ask for support. After all, you are performing a social service by making it possible for families to continue caring for their loved ones at home and avoid premature institutionalization.

8. Be friendly and compliment the caregivers on the efforts they make to provide care for their loved ones. Show concern and understanding.

OBTAINING A COMMITMENT TO ATTEND THE WORKSHOPS

Be sure to address any questions they may have about the workshops thoroughly. Be friendly and sympathetic. Be flexible in working out details. Listen carefully to any concerns that caregivers may have about their participation. Make every effort to be as accommodating as you can.

Once you have explained the project and answered all of the caregivers' questions, it is important to secure a commitment to attend the workshops. It may be premature to ask for an answer with the first contact. If there seems to be any reluctance or hesitance, allow the caregivers to take a few days to think about it before they commit themselves. It may be necessary to meet the caregivers in person to explain the project in more detail and discuss any remaining concerns they may have.

In planning your workshops, it's best to first talk to the caregivers who will attend and find a meeting time and place that is suited for all involved. Keep careful notes about their availability so that you can plan your workshops for maximum attendance.

Once a commitment has been obtained, ask if they need any special accommodations before you line up a meeting site and time. For example, do they need a ramp (for access to buildings) or do they drive at night? It is important not to inadvertently discriminate by failing to inquire.

Even after caregivers have agreed to participate, it is helpful to make a second contact and re-emphasize the advantages of participating in the workshops if doubts still remain. Caregivers must understand that they will gain useful and practical information. When a person is overwhelmed with the job of caring for a loved one with dementia, they must believe that participation will be immediately beneficial or they will not be willing to attend.

When a time and place has been selected, be sure to give all participants notification as far in advance as possible. It's also a good idea to call all caregiver participants the day before the workshop and remind them of the time and place.

FINDING A SITE TO HOLD THE WORKSHOP

It is critically important that you identify workshop sites that are in the caregiver's community and convenient for them to get to. Often public facilities such as libraries, hospitals, schools, and shopping malls may have auditoriums or community rooms which are available by advance reservation. Apartment complexes or condominiums often have clubhouses that may be available. If you work in the same community as your workshop participants, your employer may allow you to use the space after regular business hours.

In some cases, where you know some of the caregivers and they know each other (e.g., members of the same church or club), it is appropriate to hold workshops in your own home or the homes of caregivers. The latter alternative works well if a caregiver is reluctant to leave her care recipient. Let them know that they should go to no extra trouble. Simply ask if it would be alright for you and a few other caregivers to drop by for a few hours. Of course, this will only be feasible if your workshop groups are small and the other caregivers don't mind the informal atmosphere.

Consider holding your workshop at an adult day care center where respite can be provided. If you feel that this will be a workable plan, be sure to do your homework. Contact the director of the adult day care center, explain your intentions, and find out whether they are willing to cooperate.

When contacting local sites to inquire about the availability of space, be prepared to offer a choice of dates and times. Based on the careful notes you took when you talked to the caregivers about the best times for them to meet, create a preference list of dates and times, ordered from the most to the least suitable.

When you are making the arrangements, ask about the following:

1. Is the room available on the dates required?
2. Is there a fee for using the room?
3. Can the room accommodate the expected number of workshop participants?
4. Will the room have chairs and tables or desks (participants will need to do some writing)?
5. Can the facility provide a television monitor and VCR for showing recommended videos that accompany the Caregiver Lesson Plans?
6. Will someone be available to show you how to operate the equipment or can they leave written instructions for you?
7. Is the facility accessible to those with disabilities?

Discuss why the workshops are being held and how caregiver participants will benefit. You should also let them know that the workshops are provided at no charge to participants.

Once you have arranged for a training site, be sure to call the caregivers and let them know where the workshops will be held. It's a good idea to provide participants with written directions, a map, and a phone number (in case they get lost), as well as a schedule of dates and times.

PREPARING FOR THE WORKSHOP

First and foremost, there are a couple of pivotal points that will make or break a group. One is the relation between the trainer, the caregivers, and the subject matter. Another is the influence of the environment, both physical and emotional, on the group. The trainer has some, but not complete, control over both elements. One thing is for sure. If an individual feels out of place, he won't come back. It pays to make the environment as hospitable as possible. If trainers are able to bring along a few sodas and cookies (especially if they're homemade!), it indicates that you have gone the extra mile and care about your participants. In some situations, it might be possible to have a pot luck lunch or dinner to "break the ice" as people get to know each other.

Maintain a list of all caregiver participants who have agreed to attend your workshops. Get their addresses so you can send them written directions to the first workshop. (If possible, do a "dry run" to look for detours, one-way streets, or unexpected road hazards.) Also get daytime and evening phone numbers so you can call them with updates or cancellations. If it is necessary to cancel a workshop, reschedule another one as soon as possible.

One week before the workshop check to make sure you have a sufficient number of evaluation forms (if you are using them), pencils, caregiver handouts, and any audio visual materials or props for experiential exercises. Duplicate materials as necessary.

Two days before the workshop, confirm the training site, location, date, and time. Make sure that someone will be there at the appointed time to let you into the room, or get the key beforehand.

One to two days before the workshop, review the Caregiver Lesson Plans you intend to cover. This will help refresh your memory and will make you feel more comfortable going into the training. "Cue-up" any videos you will be using to the segments on the tape that you will be showing. Call all caregiver participants to remind them of the workshop and iron out any last minute problems they may have.

One day before the workshop, assemble all materials in a convenient place. On the day of the workshop arrive one-half hour before the scheduled starting time. Note the location of restrooms, water fountains, and fire exits. Test the television monitor and VCR to make sure you can play your videos. Arrange the room so that all participants will be able to see the television monitor. Set out all the materials you will be using.

HOW TO USE THE CAREGIVER LESSON PLANS (MODULES)

Now comes the actual training. Small group learning is certainly one of the best formats for adult education. The 19 Caregiver Lesson Plans (or modules) have been laid out roughly to correspond to the earlier, middle, and later stages of the disease process. Nine of the most essential modules have study questions drawn from the mini-lecture. At a minimum, you will need about eight to twelve contact hours just to cover the material in these nine modules. Probably the most convenient schedule is three to four sessions of two and a half to three hours each, but you may need to develop another kind of format to accommodate the needs of your group.

Each module is laid out as follows: The **goal** describes what it is you want to accomplish, and the **rationale** explains why you want to do so. The **educational objectives**, by contrast, are framed in terms of the learner, e.g. "By the end of this session, caregivers should be able to ...."

The **mini-lecture** will provide you with pertinent information, but there are **references and suggested readings** at the end of each chapter for further investigation. Be sure to read the study questions for the nine "essential" modules before you review the mini-lecture in preparation for the workshop. Highlight the answer to each question in the mini-lecture, so you will be sure to emphasize the point. Go over the mini-lecture several times before you give it, and do not read it! You want to tell the group about the subject matter in a conversational style. Allow them to stop you if they don't understand, and keep the atmosphere non-threatening and informal. You want to share with them, not preach to them!

There are usually several ideas for video tape under **audio-visual reinforcement**. If at all possible, have a VCR (1/2" VHS) available. Preview the tape and pick out the footage that undergirds or illustrates the mini-lecture. (Please remember to rewind the tape after each use!) Some of the suggested videos may be available at your local Alzheimer's chapter. Video material should be used to emphasize the points you want to make and break up the monotony of a lecture. It's best not to plan on showing a full length video, however, due to time constraints. Videos should not be used to substitute for the lecture material. If you feel a video is particularly worthy of viewing in its entirety, plan your time accordingly.

Last but not least is the **experiential learning** section. This section contains ideas to "drive home" the main idea(s) of the module. To quote Ben Franklin, "You involve me and I learn." Use your own judgment and pick the activity that's best for your group. Be sure to decide which activities you plan to use well ahead of time, because it may require copying, props, etc. For example, the experiential learning exercise for the module on Legal and Financial Issues involves providing examples of two versions of a durable Health Care Power of Attorney and a durable General Power of Attorney. These are among the most vital documents a caregiver can have. Be sure to bring enough copies for everyone who attends.

Many, but not all, of the modules have handouts, some of which are essential for the experiential exercises. Others (e.g., AgePages) are optional. Plan well ahead of time to determine which handouts you need to have copied.

There is variation in the length of Caregiver Lesson Plans (Modules). For example, the module on Formal Supports and Resources has so much information it may overwhelm the caregivers. This material can be personalized by inviting representatives from some of the agencies mentioned to discuss the services they have to offer. For the caregivers' future reference, try to obtain brochures from all of the community agencies which provide support and services in your area. With the shorter modules (e.g., Managing Wandering), more than one Caregiver Lesson Plan could be included in a single session.

In summary, read through all the required modules and decide how many you can include in a particular session. The only requirement is to do "earlier" modules before "middle" ones, and "middle" ones before the "later" ones.

BUILDING TRUST

In order to provide a successful workshop experience for caregivers, it is helpful to build a relationship of trust. You may be dealing with individuals who doubt your ability to help them. This skepticism derives from a variety of sources (bad experiences with service providers, questions about the usefulness of education, etc.). You must get beyond this point before you can begin to develop an atmosphere of confidentiality.

1) If caregivers feel that you have an understanding of their needs, they will be more willing to believe you can help them.

   Have the group come up with a case study (or example of a caregiving situation) that is pertinent to their particular situations. As the "case" develops, caregivers will ascribe attributions that portray their own concerns without having to voice them directly.

2) Personalizing your lessons is one way to engender trust. If you share their experiences or can relate to what they're dealing with you are more likely to be trusted.

   Ask questions like, "Has anyone in the group ever felt ________?" or "Has anyone ever had to deal with ____________?"

   Phrases like "I've been there" or "I know what it's like" will let caregivers know that you have a personal understanding of their problems. **CAUTION: If you are not or have never been a caregiver, DON'T assume you know how caregivers feel.**

3) Use yourself as an example whenever possible.

For example, with group members who may have literacy or vision problems, say "I forgot my glasses. Will someone please read this questionnaire/hand-out aloud?"

4) To allay fears at the first workshop, give the caregivers a chance to get to know you better. Talk about yourself, your experiences, and your interest in caregiver issues.

Alternatively, form an alliance with someone in the group beforehand, and arrange for this person to go to the workshop before you arrive. Have them engage in a discussion about you with other members of the group. This will give participants a chance to ask questions about you when you're not there. They can express their misgivings, doubts, or fears and be assured that you are really "on their side."

5) Pay special attention to members who seem aloof or don't contribute to group discussions. Take time during breaks to draw these individuals out and get to know them better.

Often the silent members of a group feel awkward, inadequate, or worry that they just don't belong. By getting to know them you will be better able to involve them in the group process. These efforts may also have the added benefit of enhancing their self esteem.

6) Age differences can inspire mistrust. If your workshop participants are older than you, they may imagine (or there may actually be) a generation gap.

Let older participants know that you respect them and value their wealth of experience. Avoid sounding like an expert who knows all the answers. Directly compliment participants when they make particularly insightful or wise contributions.

UNINTENTIONAL ABUSE AND NEGLECT

It is possible that some trainers may encounter a caregiver who is improperly caring for their loved one. They may have devised a coping method that is actually abusive or neglectful. For example:

1) "I just lock Laverne in the bedroom so she won't get into trouble when I go out to do the weekly grocery shopping."

2) "Dad had problems sleeping so the doctor prescribed sleeping pills. Now we can give him two or three pills and he'll sleep while we go to church."

3) "I could never get George to go to the bathroom when I wanted him to. Since I've started tying him onto the toilet he will go eventually, and he didn't before."

If you find any instances of unintentional abuse or neglect consider the following, before deciding how to proceed:

1) Caregivers are doing the best they can with what they know and what they've got. They want to provide the best possible care and devote a great deal of time and effort to the job.

   Caregivers have come to the workshop because they want to learn more and get help with their caregiving responsibilities. Their very presence is an indication of good intention.

2) People won't reveal what they know is wrong. They may be wondering if their solution is the best way to handle the situation, however.

   Praise caregivers for their intention to solve the problem ("It's good that you realize that Laverne could get into trouble without someone to watch her."). Then offer an alternative solution that is more appropriate ("It would be better if you took her shopping with you or asked someone else to do the shopping for you.")

3) You have built a trusting relationship with the caregiver and you don't want to do anything that will jeopardize that.

   Non-verbal cues speak louder than words. Be self-conscious and try not to over-react to what you have been told.

4) Consider involving the group in the problem-solving process.

   One goal of the workshops is to empower caregivers through education. They may be more willing to accept empowerment if they feel it's their own idea. If you can get caregivers to "claim" alternative approaches as their own, you are more likely to be able to promote change. This is best accomplished by reframing the question and involving caregivers in a discussion of possibilities.

Following the discussion, consider compiling the suggestions offered during the group process and making a hand-out for the next session. This will be tangible evidence of "ownership."

5) If you feel that the abusive or neglectful behavior is likely to continue and there is nothing you can do within the context of the workshop to intervene, call the Adult Protective Services Unit at your local Department of Social Services. You have an obligation to report your concerns about abuse or neglect, and you may do so anonymously.

EVALUATION

For trainers interested in demonstrating the effectiveness of caregiver workshops and their usefulness to caregivers, a workshop evaluation instrument is included at the end of this chapter. This questionnaire was administered at the end of each workshop for purposes of evaluating the current project. In addition to the workshop evaluation questionnaire, the study questions which correspond to the nine essential modules were used as pre-training and post-training tests to measure gains in knowledge. These study questions (which are included at the end of this Chapter) may be administered before and after the pertinent mini-lecture if trainers want to know how well they are communicating. Alternatively, trainers may prefer to have participants answer the study questions only at the end of the workshop as a didactic aid to reinforce key points. That is, trainers may allow time after the lecture has been delivered for participants to answer the questions and then review the answers as a group.

If you decide to evaluate your training, explain to caregivers the importance of their cooperation in completing evaluation forms. Be sure to thank caregivers for taking the time to do the paperwork necessary to evaluate the project. Caregivers may have concerns about the confidentiality of the information they provide. In order to preserve their anonymity, ask participants to choose a Caregiver Identification Number to use on all of the forms they complete. This number should be one that they can easily remember. For example, the Identification Number could be the last six digits of a caregiver's social security number, some variation of their social security number (e.g., digits in reverse order or two digits interchanged), or any other number that is easy to remember (phone number, birth date, etc.). Let participants know that they will not be identified by name on any of the questionnaires, and that their responses will be used for evaluation purposes exclusively. Just explain that you want some feedback about whether they felt the workshop was worthwhile. Also let them know that you will use the questionnaire responses in planning future workshops. Tell them that any comments they have to make (good or bad) would be appreciated.

Prior to the workshop make sure you have enough copies of all the evaluation forms to be used. It's a good idea to use different colored paper for your copies. The pre-training questionnaire should be copied on one color, the post-training questionnaire should be copied on another color, and the workshop evaluation questionnaire should be still another color. In this way, you will readily be able to ascertain that everyone is working on the same form at the same time. You should have a set of forms for each caregiver expected to attend. If necessary make extra copies for "drop in" caregivers.

Be sure to allow sufficient time for the completion of evaluation forms when you plan your workshops. Observe caregivers as they work, and assist anyone who seems to be having difficulty completing the forms. When all participants have completed the forms, collect them and check to make sure that they have used their Caregiver Identification Number on each survey.

Pre-Training and Post-Training Knowledge Questionnaires (Study Questions)

Prior to each workshop select the Caregiver Lesson Plans that you will cover during that workshop. Pre-training and post-training knowledge questionnaires (or study questions) accompany each of the nine essential Caregiver Lesson Plans (Modules 1, 2, 3, 5, 7, 9, 11, 13, & 19). At the beginning of each workshop administer all of the pre-training knowledge questionnaires which correspond to the Caregiver Lesson Plans you intend to cover. "Taking a test" could be threatening to people who haven't engaged in this kind of activity in several decades. Be sure to explain that they aren't supposed to know the answers. If they did, there would be no need for the training. Also remind them that there are no names (only Identification Numbers) and no grades.

Since these questionnaires are short, you need only allow about 10 minutes per questionnaire for completion. Read the instructions for completing the knowledge tests out loud and ask if all participants understand how to complete them. Encourage participants to ask any questions they may have about how to complete the tests. Be careful about answering questions pertaining to the content of specific knowledge questions however. You don't want to "give away" the answers. If caregivers seem confused about what is being asked, reiterate that they are not supposed to know all the answers at this point. Assure them that each question will be answered during the workshop. Note: Be sure that your lecture covers the knowledge questions.

When participants have completed the pre-training questionnaire(s), collect them making sure that they have used their Caregiver Identification Numbers. Proceed with the workshop and allow time at the end to administer the corresponding post-training questionnaire(s). Collect the post-training questionnaires, making sure that Caregiver Identification Numbers have been entered on each test. After you have collected all tests, you can go over the questions, giving the correct answer.

Note: If participants arrive late for the workshop, be sure to give them the pre-training questionnaire(s) and have them complete it immediately while you proceed with the workshop. Collect the pre-training questionnaire from them as soon as they are finished.

Gains in knowledge can be documented only when caregivers have completed both a pre-training and a post-training questionnaire. Pre-training questionnaires that cannot be matched with post-training questionnaires through corresponding Caregiver Identification Numbers are worthless for purposes of evaluation. Please make the extra effort to be sure that caregivers respond to both questionnaires.

By reviewing the pre-training and post-training questionnaires, trainers can discover whether participants are learning the workshop content. If scores are low (i.e., very little improvement from the pre-training baseline), trainers may want to simplify the lecture material, place more emphasis on their key points, or slow the rate at which material is covered.

Workshop Evaluation Questionnaires

At the same time you administer the post-training questionnaire(s) you can administer the workshop evaluation questionnaire. Following each workshop you conduct, caregivers should be asked to complete a workshop evaluation questionnaire. These surveys ask caregivers to indicate the extent to which each workshop:

1) was relevant to their particular problems and concerns as caregivers;
2) made them more aware of the availability of community resources;

3) increased the likelihood that they will access community resources in the future;
4) improved their understanding of their care recipient's psychosocial needs; and
5) enhanced their ability to provide better quality care.

The workshop evaluation questionnaire also asks questions about the general usefulness of the workshop content, the effectiveness of the presenter, and the use of audio-visual materials or handouts. Encourage caregivers to answer the open-ended questions concerning topics they would like more detailed information about, and the most and least helpful aspects of the workshop.

Since these questionnaires are short, you need only allow about 10 minutes for completion. Read the instructions for completing the workshop evaluation questionnaires out loud and ask if all participants understand how to complete them. When you collect the workshop evaluation questionnaires make sure that Caregiver Identification Numbers have been entered on each survey. If someone has to leave the workshop early, ask them to complete the workshop evaluation questionnaire before they go. Have caregivers evaluate each workshop.

Reviewing the feedback provided may help you improve your workshops and get a better idea of what caregivers want to learn. Based on input from the participants, revisions can easily be made. Don't be discouraged if caregivers are critical. You want to know what doesn't work as well as expected. All information is important, whether it is positive or negative.

CONCLUSION

At the end of this Chapter trainers are provided with: 1) a list of tips for conducting a successful workshop, 2) suggestion for outreach in African American communities, and 3) suggestions for outreach in rural communities. Trainers who follow these tips and suggestions (and adhere to the instructions provided in this Chapter) will be more effective in recruiting caregiver participants and conducting workshops. Convincing caregivers that the information you have will help them deal with their responsibilities and provide better care can be a real challenge. You may encounter skepticism ("Is this really worth my time?"), suspicion ("What is your ulterior motive?" "What's the catch?"), and frustration ("How can I possibly take on any more than I already have to deal with?"). Effective trainers will be prepared for these responses and counter negativity with a sincere willingness to help. If you take the time to develop a relationship with caregivers, the reward of helping others help themselves will be well worth the effort.

ADDENDUM

Do You Suspect Someone You Know May Have Alzheimer's Disease?

Are You Worried About An Older Loved One Who Seems:

- * frequently confused
- * exceptionally moody
- * to have increasingly more trouble managing money and household tasks
- * forgetful of important things
- * angered at the "least little thing"
- * unable to recall recent events

If your answer to any of these questions is "yes", you should attend the FREE community workshops to be offered in rural areas. To learn more about caring for loved ones with any of these symptoms, please contact your pastor or:

Assistance with transportation and arranging for adult sitters is available

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* exceptionally moody
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* forgetful of important things
* angered at the "least little thing"
* unable to recall recent events

If your answer to any of these questions is "yes", you should attend the FREE community workshops offered to African American families and churches. To learn more about caring for loved ones with any of these symptoms, please contact your pastor or:

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Do You Suspect Someone You Know May Have Alzheimer's Disease?

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SAMPLE PRESS RELEASE
(Your Letterhead)

Release Date:_________ Contact: ___(Name)___

___(Phone)___

COMMUNITY INFORMATION SESSION FOR RURAL AND/OR MINORITY CAREGIVERS OF ELDERS WITH DEMENTIA

An innovative program to educate rural and/or African American family members caring for elders with Alzheimer's Disease and other dementias will be offered by ___ ____(Your agency)____________________________. The project will be offered in local communities in ______(Your area)____________________.

The program consists of a series of workshops designed to help families learn more about Alzheimer's Disease (or other dementias) and the community resources available to support them. The workshops will be organized to correspond with the progressive nature of dementia, so that caregivers can get the information they need, when they need it. Some of the topics that will be covered are medications and treatment, legal and financial issues, personal care skills, dealing with communication and behavior problems, safety and environmental adaptations, and caring for the caregiver.

For more information, call

____________________________ at ________________________

TIPS FOR SETTING UP A SUCCESSFUL WORKSHOP

1. Select a site that is conveniently located for the family caregivers you have recruited. If the group is very small (for example, if several families have been identified to participate) you may have the workshops in one of the participant's home.

2. Ask your family caregiver recruits about the best time to hold your workshops and schedule them to meet the needs of the majority.

3. If the group of family caregivers attending the workshops is very large, make sure the site can accommodate all of those who will attend.

4. Name tags are helpful with large groups of participants. If you purchase self-adhering tags, bring magic markers and ask participants to print in large letters the name they wish to be called.

5. Serving refreshments can encourage participation. Investigate the possibility of having food donated (for example, ask the local Fire Department to furnish Brunswick Stew). This strategy will be especially popular in rural areas.

6. If you have recruited your family caregivers through a local church, you may consider scheduling your workshops on Sunday afternoons after church services and following a potluck lunch.

7. Be sure you have made enough copies of all handouts and evaluation forms for each workshop. Bring pencils!

8. Schedule your workshops well in advance and call all of your recruits personally to let them know where and when the workshops will be held. It's a good idea to follow your phone call with a written invitation including clear directions to the workshop site.

9. Plan the content of your workshops carefully. Review the material to be presented and make sure you have scheduled enough time to cover all the information you intend to present.

SUGGESTIONS FOR A SUCCESSFUL OUTREACH PROGRAM IN AFRICAN AMERICAN COMMUNITIES

Adapted from material provided by Edna Ballard, Duke University Alzheimer's Disease Research Center

1. Ethnicity matters - people are equal but different. Learn as much as you can about cultural differences in history, tradition, and health practices.

   Be mindful of social expectations or behaviors which may offend older African Americans. Use last names and proper titles. Avoid labels such as "non-White".

   Be prepared to offer help to caregivers on their own terms and address what they feel are the important problems. Families want professionals to be competent, knowledgeable, and sensitive about the difficulties they are facing. Respect their approach to working with their loved ones.

2. People generally do not respond to information about services until they reach the "point-of-pain" - that point where their situation becomes painful enough to require action.

   Try to impress upon them the importance of being prepared for what is to come and the value of knowing what they can do before a crisis situation arises.

3. A major barrier to service use in the minority community is a lack of familiarity with services and providers and/or a lack of trust in the agencies providing services. Trust is a critical element in the decision to use service.

   Allow families to explore their fears, questions, misgivings, etc. Explain that the workshops will be planned to meet their specific needs. Never promise what you can't deliver and always deliver what you promise.

4. Another barrier is the cultural "sacred cows", which make service use incompatible with beliefs and values of the individual, for example, "we take care of our own." Being helpful in these instances requires understanding the cultural "musts" and "must nots" of the group and offering service in a way which becomes acceptable.

   Let the caregivers know that you have an understanding of their traditions, values and beliefs. Offer help in a manner that is acceptable to the family. Inform them that the workshops are designed to be useful to families in African American communities.

5. Practical considerations often have important consequences. Creativity and flexibility about when and where services are offered may increase participation.

   Let the families know that you intend to offer the workshops at a place and time that is convenient for those attending.

6. Families often do not define themselves as "caregivers."

   Be mindful of jargon or words which may not be familiar, for example, "caregivers." Refer instead to families who take care of an older relative or family member.

7. Families may not be aware that their loved ones have Alzheimer's Disease or another dementia. Multi-infarct stroke is a common cause of dementia among African Americans.

   Refer instead to behavioral symptoms such as memory loss, mood changes, judgment difficulties, and temperamental outbursts.

8. There are many different kinds of families in the African American community, including persons unrelated or distantly related by blood or marriage who are nonetheless considered to be family and provide care. For example, grandchildren often willingly assume primary caregiving responsibilities.

   Focus on the caregiving needs of the family. The "kind" of family is irrelevant except, where there is a question of legal authority in making decisions for the person with Alzheimer's Disease.

9. The primary caregiver may be reluctant to participate in the workshops, especially if the person with AD or other family members object. Some family members may feel that the workshops are unnecessary, particularly in the early stages when the person's problems are not obvious.

   Be supportive of the caregiver's decision to participate, despite objections from others. It helps to remind the caregiver that there are "no right or wrong answers" for many caregiving dilemmas. The caregivers must decide what is best for themselves.

10. People who are unserved deserve to be reached. It is important to communicate the benefits of caregiver education. Some caregivers may believe that Medicare will pay for everything.

    Explain the benefits of workshop participation and why they need to know about supportive community services. Let them know that some service agencies are making special efforts to serve minorities better by training personnel to be knowledgeable of cultural considerations.

SUGGESTIONS FOR A SUCCESSFUL OUTREACH PROGRAM IN RURAL COMMUNITIES

Adapted from material provided by Edna Ballard, Duke University Alzheimer's Disease Research Center

1. The rural elderly are typically underserved. As a consequence, caregiving families may be suspicious of offers to help.

   Allow families to explore their fears, questions, misgivings, etc. Explain that the workshops will be planned to meet their specific needs. Never promise what you can't deliver and always deliver what you promise.

2. Isolated, rural families may believe that they can't do anything to improve their caregiving situation. They may think that the situation is unchangeable, for example, "It's all in God's hands."

   Emphasize the benefits of workshop participation and why they need to know about supportive community services. Families need to become empowered and learn that they can exert control over their lives.

3. Rural families tend to be less educated. Non-scientific views of health and illness are not uncommon. Religious traditions, local folklore, and reliance on herbal medicines may all be barriers to adequate health care.

   Be prepared to offer help to caregivers on their own terms and address what they feel are the important problems. Respect their approach to working with their loved ones. Let the caregivers know that you have an understanding of their traditions, values and beliefs. Offer help in a manner that is acceptable to the family. Inform them that the workshops are designed to be useful to those in rural communities.

4. People generally do not respond to information about services until they reach the "point-of-pain" - that point where their situation becomes painful enough to require action.

   Try to impress upon them the importance of being prepared for what is to come and the value of knowing what they can do before a crisis situation arises.

5. Practical considerations often have important consequences. Creativity and flexibility about when and where services are offered may increase participation.

   Let the families know that you intend to offer the workshops at a place and time that is convenient for those attending.

6. Families often do not define themselves as "caregivers."

Be mindful of jargon or words which may not be familiar, for example, "caregivers." Refer instead to families who take care of an older relative or family member.

7. Families may not be aware that their care recipients have Alzheimer's Disease or another dementia.

   Refer instead to behavioral symptoms such as memory loss, mood changes, judgment difficulties, and temperamental outbursts.

8. The primary caregiver may be reluctant to participate in the workshops, especially if the individual with AD or other family members object. Some family members may feel that the workshops are unnecessary, particularly in the early stages when the person's problems are not obvious.

   Be supportive of the caregiver's decision to participate, despite objections from others. It helps to remind the caregiver that there are "no right or wrong answers" for many caregiving dilemmas. The caregivers must decide what is best for themselves.

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   Explain the benefits of the workshop participation and why they need to know about supportive community services.

Answers to Evaluation (Study) Questions

Module 1 (An Overview: Dementia and Caregiver Issues)

1. c
2. d
3. c
4. b
5. T
6. T
7. T
8. F

Module 2 (Caregiver Burden)

1. b
2. b
3. c
4. a
5. T
6. F
7. T

Module 3 (Coping with Caregiver Stress)

1. e
2. a
3. c
4. a
5. b

Module 5 (Legal and Financial Issues)

1. d
2. a
3. d
4. F
5. T

Module 7 (Managing the Daily Routine)

1. c
2. c
3. a
4. F
5. F
6. T
7. F

Module 9 (Formal Supports and Resources)

1. a
2. b
3. b
4. T
5. T
6. F
7. T

Module 11 (Managing Resistive Behavior)

1. d
2. c
3. c
4. F
5. F
6. T

Module 13 (Communicating with the Person with Alzheimer's Disease)

1. d
2. a
3. a
4. F
5. T
6. T

Module 19 (24 Hour Care)

1. b
2. c
3. c
4. T
5. T
6. F
7. F

MODULE 1: AN OVERVIEW: DEMENTIA AND CAREGIVER ISSUES
PRE-TEST QUESTIONS

Caregiver Identification Number________________________________

For each of the items which follow, circle the letter beside the best answer. Be sure to respond to each item. If you aren't sure, make your best guess.

1. Dementia is:
   a. the same as senility.
   b. a normal part of aging.
   c. a loss of intellectual ability that interferes with daily functioning.
   d. all of the above.

2. Alzheimer's Disease is:
   a. an age-related, chronic cognitive dysfunction.
   b. the most common form of dementia.
   c. a progressive, degenerative brain disease.
   d. all of the above.

3. The most conclusive method of diagnosing Alzheimer's Disease:
   a. is accomplished through a CAT scan.
   b. is based on the results of IQ tests.
   c. can be made only upon examination of brain tissue at autopsy.

4. ________________ is the primary symptom of Alzheimer's Disease in the early stages.
   a. Violent outbursts
   b. Forgetfulness
   c. Wandering
   d. Seeing things that aren't there

In the space provided beside each item write the words "True" or "False" to indicate whether you think the statement is true or false.

_____ 5. Alzheimer's Disease is diagnosed by excluding other possible causes.

_____ 6. Alzheimer's Disease causes cells in the brain to die.

_____ 7. Alzheimer's Disease can last from two to twenty years.

_____ 8. The onset of Alzheimer's Disease is usually very sudden rather than gradual.

MODULE 1: AN OVERVIEW: DEMENTIA AND CAREGIVER ISSUES
POST-TEST QUESTIONS

Caregiver Identification Number____________________________________

For each of the items which follow, circle the letter beside the best answer. Be sure to respond to each item. If you aren't sure, make your best guess.

1. Dementia is:
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MODULE 2: CARING FOR THE CAREGIVER
PRE-TEST QUESTIONS

Caregiver Identification Number____________________________________

For each of the items which follow, circle the letter beside the best answer. Be sure to respond to each item. If you aren't sure, make your best guess.

1. The effective caregiver fills all of the following roles except:
   a. manager.
   b. enabler.
   c. learner.
   d. observer.

2. Which of the following is not one of the three major components of caregiver "burnout"?
   a. emotional exhaustion
   b. physical exhaustion
   c. reduced personal accomplishments
   d. depersonalization

3. The development of a negative and insensitive attitude about the patient is called:
   a. caregiver burden
   b. caregiver burnout
   c. depersonalization
   d. the mea culpa syndrome

4. The physical, financial, and emotional stress of caring for a disabled elderly family member is called:
   a. caregiver burden
   b. caregiver burnout
   c. depersonalization
   d. the mea culpa syndrome

In the space provided beside each item write the words "True" or "False" to indicate whether you think the statement is true or false.

_____ 5. The basic goal of caregiving is to ensure the patient's comfort and safety, while promoting emotional stability and self-esteem.

_____ 6. Abuse by a caregiver is the most frequent type of maltreatment of older and incapacitated adults.

_____ 7. As many as 65% of family caregivers experience symptoms of depression.

MODULE 2: CARING FOR THE CAREGIVER
POST-TEST QUESTIONS

Caregiver Identification Number____________________________________

For each of the items which follow, circle the letter beside the best answer. Be sure to respond to each item. If you aren't sure, make your best guess.

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_____ 7. As many as 65% of family caregivers experience symptoms of depression.

MODULE 3: COPING WITH CAREGIVER STRESS
PRE-TEST QUESTIONS

Caregiver Identification Number________________________________

For each of the items which follow, circle the letter beside the best answer. Be sure to respond to each item. If you aren't sure, make your best guess.

1. Caregivers can get respite or relief from their caregiving responsibilities by:
   a. finding adult day care.
   b. hiring a homecare aide.
   c. having someone else stay with the care recipient for a few hours.
   d. retreat to a "hermit spot" or "quiet hideout."
   e. all of the above.

2. ___________ is the invigorating and challenging kind of stress, while distress is the negative kind of stress to be avoided.
   a. Eustress
   b. Mistress
   c. Unstress
   d. Envircstress

3. The _______________________ syndrome occurs when the body reacts to threat and prepares to either confront of escape it.
   a. mea culpa
   b. give or take
   c. fight or flight
   d. make or break

4. All of the following are symptoms that indicate stress, except:
   a. dry palms and warm hands
   b. pounding heart
   c. nightmares
   d. change in appetite

5. __________ is a stress-relieving technique based on the theory that tense muscles are the body's response to anxiety.
   a. Visualization or guided imagery
   b. Progressive relaxation
   c. Deep abdominal breathing

MODULE 3: COPING WITH CAREGIVER STRESS
POST-TEST QUESTIONS

Caregiver Identification Number____

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   c. Deep abdominal breathing

MODULE 5: LEGAL AND FINANCIAL ISSUES
PRE-TEST QUESTIONS

Caregiver Identification Number________________________________

For each of the items which follow, circle the letter beside the best answer. Be sure to respond to each item. If you aren't sure, make your best guess.

1. Examples of advance directives are:
    a. will
    b. Health Care Power of Attorney (medical affairs)
    c. General Power of Attorney (financial affairs)
    d. all of the above.

2. A durable health care power of attorney:
    a. will still be valid after a person becomes incapacitated.
    b. must be witnessed by at least one blood relative.
    c. must be notarized.
    d. must be drawn up by an attorney.

3. Some of the legal and financial consequences of Alzheimer's Disease include the fact that the person with Alzheimer's Disease eventually:
    a. will not be able to handle financial and business affairs.
    b. will not be able to make his/her own health care decisions.
    c. will have to use savings to cover help that is not covered by insurance.
    d. all of the above.

In the space provided beside each item write the words "True" or "False" to indicate whether you think the statement is true or false.

_____ 4. After a loved one has been diagnosed with dementia, a caregiver should immediately seek legal guardianship.

_____ 5. The term "durable" refers to the fact that an instrument will still be valid if a person becomes incompetent.

MODULE 5: LEGAL AND FINANCIAL ISSUES
POST-TEST QUESTIONS

Caregiver Identification Number________________________________

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MODULE 7: MANAGING THE DAILY ROUTINE
PRE-TEST QUESTIONS

Caregiver Identification Number________________________________

For each of the items which follow, circle the letter beside the best answer. Be sure to respond to each item. If you aren't sure, make your best guess.

1. The task of dressing the person with dementia can best be facilitated by:
   a. taking over the task if the person is too slow.
   b. offering several choices of clothing.
   c. laying out articles of clothing in the order they are to be put on.
   d. all of the above.

2. The calorie requirements of an older person are ______________ the calorie requirements of a younger person.
   a. the same as
   b. greater than
   c. less than

3. ___________ is a series of mixed messages sent from the brain to the body.
   a. Apraxia
   b. Apoxia
   c. Dispraxia
   d. Dispoxia

In the space provided beside each item write the words "True" or "False" to indicate whether you think the statement is true or false.

_____ 4. Using bath oil or bubble bath is a good idea because it can make the bathing experience more enjoyable.

_____ 5. When patient's resist assistance with Activities of Daily Living, it is recommended that caregivers change the daily routine as much as possible.

_____ 6. Persons with Alzheimer's Disease or other dementias lose the ability to gauge temperature and sense hot or cold.

_____ 7. Since grooming activities such as shaving and brushing teeth are not complex, they are easily performed by persons with Alzheimer's Disease or other dementias.

MODULE 7: MANAGING THE DAILY ROUTINE
POST-TEST QUESTIONS

Caregiver Identification Number____________________________________

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MODULE 9: FORMAL SUPPORTS AND RESOURCES
PRE-TEST QUESTIONS

Caregiver Identification Number________________________________

For each of the items which follow, circle the letter beside the best answer. Be sure to respond to each item. If you aren't sure, make your best guess.

1. When calling to find formal assistance with caregiving responsibilities caregivers should do all of the following, except:
   a. try to call in the late afternoon.
   b. be as specific as possible about the service you want.
   c. be polite but firm.
   d. get the name of everyone you talk to.
   e. be prepared for the intake interview.

2. Medicare Part B helps pay for all of the following except:
   a. physician services.
   b. inpatient hospital care.
   c. outpatient mental health services.
   d. mammography.

3. Rural Area Agencies on Aging typically have budgets and staff which are ______________ Area Agencies on Aging in urban areas.
   a. larger than
   b. smaller than
   c. the same size as

In the space provided beside each item write the words "True" or "False" to indicate whether you think the statement is true or false.

_____ 4. The Older Americans Act dictates that the elderly have certain rights and privileges that should be provided for by national, state, and local governments.

_____ 5. A health care power of attorney is more comprehensive than a living will.

_____ 6. Your local Alzheimer's Disease chapter does not provide services to patients until they are in the middle or late stages of the disease.

_____ 7. If you are eligible for Medicaid because of low income, you will have benefits in addition to those provided by Medicare insurance.

MODULE 9: FORMAL SUPPORTS AND RESOURCES
POST-TEST QUESTIONS

Caregiver Identification Number________________________________

For each of the items which follow, circle the letter beside the best answer. Be sure to respond to each item. If you aren't sure, make your best guess.

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MODULE 11: MANAGING RESISTIVE BEHAVIOR ASSOCIATED WITH ADLs
PRE-TEST QUESTIONS

Caregiver Identification Number________________________________

For each of the items which follow, circle the letter beside the best answer. Be sure to respond to each item. If you aren't sure, make your best guess.

1. Persons with dementia may resist bathing because they:
   a. are depressed.
   b. fear water.
   c. are embarrassed to be undressed.
   d. all of the above.

2. True incontinence of bowel and/or bladder is common among Alzheimer's patients during ____________ stages of the disease.
   a. the earlier
   b. the middle
   c. the later
   d. all

3. When patients have trouble performing Activities of Daily Living, it's a good idea to:
   a. insist that they let you do things for them even if they are capable.
   b. give them a detailed list of instructions to follow.
   c. observe their attempts to perform the activities and provide cues when needed.
   d. all of the above.

In the space provided beside each item write the words "True" or "False" to indicate whether you think the statement is true or false.

_____ 4. One way to cope with incontinence is to restrict water intake to three cups of liquid per day.

_____ 5. Laying out a wide variety of different foods on the table at mealtime will help with mealtime difficulties.

_____ 6. Proper dressing and grooming is important to fostering the patient's self esteem.

MODULE 11: MANAGING RESISTIVE BEHAVIOR ASSOCIATED WITH ADLs
POST-TEST QUESTIONS

Caregiver Identification Number________________________________

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MODULE 13: COMMUNICATING WITH THE PERSON WHO HAS AD
PRE-TEST QUESTIONS

Caregiver Identification Number____

For each of the items which follow, circle the letter beside the best answer. Be sure to respond to each item. If you aren't sure, make your best guess.

1. Aphasia refers to an inability to:
    a. express thoughts in language.
    b. understand the spoken word.
    c. recognize a word or phrase.
    d. all of the above.

2. A person with dementia may exhibit all of the following language problems, except:
    a. stuttering.
    b. anomia.
    c. aphasia.
    d. perseveration.

3. A person with dementia loses the ability to understand what you are saying:
    a. long after they have lost the ability to communicate coherently.
    b. at the same time they lose the ability to communicate coherently.
    c. long before they have lost the ability to communicate coherently.

In the space provided beside each item write the words "True" or "False" to indicate whether you think the statement is true or false.

_____ 4. Using "baby talk" is helpful when communicating with a person with dementia who is experiencing language difficulty.

_____ 5. Reducing background noise may help when communicating with a person with dementia who is experiencing language difficulty.

_____ 6. Even when it seems that you are not getting through to the patient, it's important to keep talking to them.

MODULE 13: COMMUNICATING WITH THE PERSON WHO HAS AD
POST-TEST QUESTIONS

Caregiver Identification Number________________________________

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MODULE 19: 24 HOUR CARE
PRE-TEST QUESTIONS

Caregiver Identification Number________________________________

For each of the items which follow, circle the letter beside the best answer. Be sure to respond to each item. If you aren't sure, make your best guess.

1. According to a study conducted by the University of California (1988-90), caring for an institutionalized patient with Alzheimer's Disease costs about:
   a. $25,000 a year.
   b. $50,000 a year.
   c. $75,000 a year.
   d. $100,000 a year.

2. The member of the health team who spends more time with the patient than anyone else is the:
   a. nursing home administrator.
   b. activity director.
   c. nurse aide.
   d. physical therapist.
   e. occupational therapist.

3. The decision about when nursing home placement is appropriate should be made by:
   a. the caregiver alone.
   b. the patient alone.
   c. the entire family.
   d. the nursing home staff.

In the space provided beside each item write the words "True" or "False" to indicate whether you think the statement is true or false.

_____ 4. Geographical proximity is of primary importance when evaluating placement options.

_____ 5. Many Alzheimer's patients do better in a structured environment with caring professionals to provide physical, emotional, and social care.

_____ 6. The family caregiver is usually discouraged from participating in care plan conferences when a nursing home placement is made.

_____ 7. The person with Alzheimer's adjusts better to nursing home placement if there are no reminders of home.

MODULE 19: 24 HOUR CARE
POST-TEST QUESTIONS

Caregiver Identification Number____

For each of the items which follow, circle the letter beside the best answer. Be sure to respond to each item. If you aren't sure, make your best guess.

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   b. the patient alone.
   c. the entire family.
   d. the nursing home staff.

In the space provided beside each item write the words "True" or "False" to indicate whether you think the statement is true or false.

_____ 4. Geographical proximity is of primary importance when evaluating placement options.

_____ 5. Many Alzheimer's patients do better in a structured environment with caring professionals to provide physical, emotional, and social care.

_____ 6. The family caregiver is usually discouraged from participating in care plan conferences when a nursing home placement is made.

_____ 7. The person with Alzheimer's adjusts better to nursing home placement if there are no reminders of home.

Answers to Evaluation (Study) Questions

Module 1 (An Overview: Dementia and Caregiver Issues)

1. c
2. d
3. c
4. b
5. T
6. T
7. T
8. F

Module 2 (Caregiver Burden)

1. b
2. b
3. c
4. a
5. T
6. F
7. T

Module 3 (Coping with Caregiver Stress)

1. e
2. a
3. c
4. a
5. b

Module 5 (Legal and Financial Issues)

1. d
2. a
3. d
4. F
5. T

Module 7 (Managing the Daily Routine)

1. c
2. c
3. a
4. F
5. F
6. T
7. F

Module 9 (Formal Supports and Resources)

1. a
2. b
3. b
4. T
5. T
6. F
7. T

Module 11 (Managing Resistive Behavior)

1. d
2. c
3. c
4. F
5. F
6. T

Module 13 (Communicating with the Person with Alzheimer's Disease)

1. d
2. a
3. a
4. F
5. T
6. T

Module 19 (24 Hour Care)

1. b
2. c
3. c
4. T
5. T
6. F
7. F

Workshop Evaluation Questionnaire
Workshop Number ____

Caregiver Identification Number______________________________

Please take a few minutes to answer the following questionnaire. We want to find out if this workshop was helpful to you and discover ways to make it more beneficial in the future. There are no right or wrong answers and your responses will remain confidential. You will not be identified personally in any way.

1. What is your gender? Male Female

2. What is your racial background?

White Black Other______________________
(please specify)

3. Where do you live? Rural area Urban area Suburban area

Use the scale which follows and place the number that corresponds with your answer in the blank beside each question.

1 = Not at all
2 = A little
3 = Somewhat
4 = A lot
5 = Extremely

_____ 4. Was the material covered in this workshop relevant to your particular problems and concerns as a caregiver?

_____ 5. Did attending this workshop make you more aware of help that is available in the community (that is, service agencies and organizations)?

_____ 6. After attending this workshop are you more likely to use help that is available in the community (for example, your local Alzheimer's Association or Area Agency on Aging)?

_____ 7. Did attending this workshop provide you with a better understanding of how the person you care for feels?

_____ 8. Did attending this workshop provide you with a better understanding of how you feel about the person you care for?

1 = Not at all
2 = A little
3 = Somewhat
4 = A lot
5 = Extremely

_____ 9. Did attending this workshop provide you with a better understanding of how you can help the person you care for live a happier life?

_____ 10. After attending this workshop do you feel that you have learned some things that will help you be a better caregiver?

_____ 11. In general, how useful did you find the material presented in this workshop?

_____ 12. Overall, how effective do you think the trainer was in communicating the material covered?

13. Did the trainer distribute any handout material for you to keep?

Yes No

_____ If yes, how useful did you find this handout material (use scale)?

14. Did the trainer show any videos?

Yes No

_____ If yes, how useful did you find the videos (use the scale above)?

15. What was the most helpful aspect of this workshop?

____

____

____

14. What was the least helpful aspect of this workshop?

____

____

____

Part II

Training for Caregivers: Lesson Plans (Modules)

After 23 years as a volunteer with the Providence Forge Volunteer Rescue Squad, Dorothy Morris had dealt with almost every kind of emergency, but nothing prepared her for dealing with the subtle onset of her mother's Alzheimer's Disease in 1987. Being in a rural area about 20 miles east of Richmond, she initially had difficulty finding the kinds of in-home services her mother needed, and ultimately retired in 1991 to be a fulltime caregiver. After she "discovered" the Capital Area Agency on Aging (CAAA), she was able to locate a number of helpful community resources, including the Virginia Center on Aging's train-the-trainer project. Because of her personal experience, she was an ideal candidate for training. After her training, not only did she organize and conduct a caregiver workshop series, but she also became a support group leader for the Alzheimer's Association - Greater Richmond Chapter. The CAAA arranged for her to be on the local evening news to raise awareness about persons with dementia and their family caregivers. As a trainer with first hand experience, she has been an invaluable resource to others in her rural community dealing with dementia. In reflecting on her own experience and how it has enabled her to help others, "Dottie" says, "Educating myself about the disease and learning how to cope with the stress has been the secret for me. Developing a sense of humor, keeping a positive attitude, and having faith have been my encouragement. I want to pass along to others what has been given to me through help from the CAAA and the Virginia Center on Aging. I'm grateful for the opportunity to relate my personal experiences to others. I hope it will encourage them to become trainers or support group leaders so that they, too, can be gratified by helping others."

Carlie Collier

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The Earlier Stages

Module 1: An Overview: Dementia and Caregiving Issues
Module 2: Caring for the Caregiver
Module 3: Coping with Caregiver Stress
Module 4: Sharing Responsibilities
Module 5: Legal and Financial Issues
Module 6: The Grieving Process

Module 1: An Overview: Dementia and Caregiver Issues

GOAL: To understand the progressive nature of Alzheimer's Disease and its effects on both the person with the disease and the family caregiver(s).

RATIONALE: Family caregivers who are knowledgeable about Alzheimer's Disease (e.g., diagnosis, symptoms, troublesome behaviors, legal and financial implications, medical and custodial needs, effects of medications and alcohol, etc.) as well as the effects of Alzheimer's Disease on themselves (e.g., stress, burnout, grieving, etc.) will be better able to know what they require (e.g., respite, homecare, support group, education, etc.) and when they need it (earlier, middle or later stages).

EDUCATIONAL OBJECTIVES: At the end of this module, caregivers should be able to:

1) Describe the progressive nature of Alzheimer's Disease and characterize earlier, middle and later stages.
2) Know what kind of preparation is needed to deal effectively with changes that occur as the disease progresses.
3) Know what is involved in reaching a diagnosis of "probable Alzheimer's Disease."

MINI-LECTURE:

First, let's explain the global term "dementia," of which Alzheimer's Disease is the most common kind. There are some other related disorders as well. Then we will zero in on Alzheimer's Disease in particular and examine the progressive nature of the disease. Finally, we will discuss how Alzheimer's Disease affects the whole family, especially the person who is mainly responsible for the daily needs of the care recipient. The person with the most responsibility is known as the primary caregiver. Let's focus our discussion through a series of questions.

First of all, what is dementia?

Dementia is the loss of intellect (such as thinking, remembering, and reasoning) that interferes with daily functioning. Dementia is not a disease itself, but a group of symptoms that may be present in certain diseases and conditions. For a diagnosis of dementia, there must be impairment of short term memory (e.g.

remembering your home telephone number), as well as long term memory (e.g. remembering the date of your anniversary). In addition, at least one of the following symptoms must be obvious:

1) Changes in personality, mood, and behavior
2) Difficulty with problem solving and abstract thinking
3) Impaired judgment
4) Specific disturbances of higher brain functioning.

These disturbances must interfere with social activities or relationships and there must be evidence of physical cause (Arizona Long Term Care Gerontology Center, 1990; Alzheimer's Association, 1992).

Dementia is NOT a normal part of aging. It is NOT hardening of the arteries and it is NOT "senility." There are over 50 causes of dementia, many of which are reversible. It is important to rule out the reversible causes with a thorough check-up. However, the dementia caused by Alzheimer's Disease and some related diseases is not reversible (Boyd, Frieden, Higley, & Spencer, 1989).

Alzheimer's is the most common kind of dementia, but just exactly what is it?

It is a chronic, age related, disease that attacks the brain and causes problems with memory, thinking and behavior. It affects as many as four millon adults in the United States, and strikes both men and women fairly equally. (Note: Throughout the text, the pronouns "he" and "she" will be used interchangeably.)

Alzheimer's Disease usually has a gradual onset. Problems remembering recent events and difficulty performing familiar tasks are early symptoms. The person with Alzheimer's may also experience confusion, personality change, behavior change, impaired judgment, and difficulty finding words, finishing thoughts or following directions. How quickly these changes occur will vary from person to person, but the disease eventually leaves its victims totally unable to care for themselves.

Alzheimer's Disease causes cells in the brain, called neurons, to die. Twisted fibers in the neurons (neurofibrillary tangles) and debris from broken neurons (neuritic plaques) appear. Plaques interfere with a brain cell's ability to receive and transmit messages to other neurons (Reisberg, 1981). There are also changes in the chemicals found in the brain (neurotransmitters) which allow cells to talk to each other.

Dr. Alois Alzheimer was the first person to describe the relation between plaques and tangles with the behavior and that is why the disorder bears his name. Currently there is no treatment available to stop or reverse the mental deterioration characteristic of Alzheimer's Disease.

How is Alzheimer's Disease diagnosed?

It is diagnosed by excluding other possible causes for the behavior. Since there is no one test to identify the disease, several tests must be performed along with a complete physical exam. Neurological exams may be required in addition to psychological or psychiatric exams. Detailed family and social histories should be taken to identify any drug or alcohol problems that may cause signs of dementia. By ruling out other causes for the dementia symptoms, a diagnosis of Alzheimer's Disease can result with some degree of certainty.

With a diagnosis of Alzheimer's Disease, what can the family expect?

While no two people with AD exhibit the same symptoms, there are some common characteristic behaviors. The course of Alzheimer's Disease is often described in terms of earlier, middle, and later stages. The symptoms associated with each stage develop over time, and the stages, along with their basic symptoms, often overlap. The disease process is not predictable or uniform, and **the description of stages are general guidelines.**

The EARLIER STAGES are referred to as The "Forgetfulness Phase" and typically last from two-four years. During the earlier stages of the disease, the person with Alzheimer's may know something is wrong while hiding it from others. Often symptoms are overlooked or dismissed. Although the person with AD is usually the first to notice a problem, eventually the family and close friends become aware that "something is wrong." Often the symptoms are first noticed after a stressful event has occurred. A change in residence, illness, or even taking a trip can be taxing for someone in the earlier stages of dementia. Often a crisis occurs and forces family members to seek a medical evaluation.

Forgetfulness is the primary symptom. **It's important to realize that memory loss alone is not a sign of Alzheimer's Disease.** Many people experience some difficulty remembering things as they age. In Alzheimer's Disease, however, the problem becomes steadily worse and is accompanied by other symptoms. There may be subtle personality changes and signs of depression. In addition to depression the person may:

1) Be much slower in speaking and understanding;
2) Have great difficulty making decisions and plans;
3) Be unable to calculate;
4) Become increasingly self-absorbed;
5) Be insensitive to feeling of others;
6) Avoid situations that may lead to failure; and
7) Lose the thread of a story.

While there is some decline during the earlier stages, it's important to remember that persons with AD may still be able to learn new things and perform daily care activities with little or no assistance. On the other hand they may need supervision with specific activities, such as meal preparation.

People who live independently are vulnerable during the earlier stages of AD. The inability to recall significant personal information is not only frustrating, but dangerous for the forgetful individual. Accidents are not uncommon. Denial is a powerful defense mechanism, protecting persons with AD from coming to terms with their condition. Eventually it becomes apparent that something is terribly wrong. The result is anger, suspicion, or periodic crying. The onset of depression is a good indication that there is a need for medical treatment. **There is effective treatment for the symptoms of depression.**

The MIDDLE STAGES are thought of as the "Confusional Phase" and typically last from two-twelve years. As the disease progresses, persons with AD can no longer hide their symptoms from others. Memory losses become more frequent and more profound. There is little doubt that a serious problem exists. By the end of this phase, nearly all recent and some past memories have been lost. In the middle stages, those with AD become easily confused and many cannot be left alone. Personality changes during the middle stages may be striking. Anger and frustration can accompany the inability to perform activities of daily living, such as bathing, grooming, eating and toileting. Hostile behavior (i.e.,"acting out") may be the consequence of being unable to understand things or make oneself understood. Being unable to figure out and cope with the world can make people extremely nervous and anxious.

By the middle stages the person with AD is obviously disabled. They may exhibit:

1) Markedly changed behavior;
2) Uncertainty as to how to act;
3) The need to have directions repeated;

4) Poor or failing memory of recent past;
5) Astonishingly clear memory of distant past;
6 Disorientation to time and place;
7) Use of invented words;
8) Misidentification of familiar people; and
9) Lethargy.

Many behavioral symptoms which appear in the middle stages are the result of changes in the brain. Rather than withdrawing, the person with Alzheimer's Disease may become agitated, violent, paranoid, or delusional. Obsessive behavior, such as performing a simple activity repeatedly, may also occur. It's important to remember that some symptoms which appear during this phase are medically treatable. Physicians should be consulted about the best methods of treating and coping with mood swings and behavior problems.

The LATER STAGES, or "Dependent Phase," typically last about one year and ends with death. People with AD become severely disoriented during the later stages. They may be physically able to do certain activities, but lack the mental capacity to pursue them purposefully. Late in the disease process it becomes difficult to tell how they really feel, or if they sense anything at all. This does not mean that they have lost the ability to experience pleasure or pain. They have a tendency to become withdrawn and unresponsive to others. It is sometimes said that the person who "used to be there" no longer exists. Extreme physical disability is not uncommon. True incontinence may also develop. The person with AD eventually becomes completely dependent on the caregiver. Placement in a nursing home is usually necessary because of the scope of care required.

In this phase, help is needed with simple activities of daily living. The person with AD may:

1) Be apathetic;
2) Have poor remote or recent memory;
3) Be unable to find their way;
4) Be incontinent;
5) Repeat certain phrases and syllables;
6) Be unable to recognize familiar people; and
7) Exhibit progressive immobility/gait disturbances.

Brain cell deterioration and denial protect the individual from experiencing the full emotional impact of dementia in the later stages. Some continue to laugh, smile, and appear happy. There are reports of late-phase persons with AD who are still able to attend and enjoy important family events, like graduations or weddings. Human contact is important to the person with Alzheimer's throughout the course of the disease, even in the very last stages. Attention, consideration, and expressions of love provide emotional and physical stimulation. There is some suggestion that conversation (even if it is completely one-sided) may help keep the person with AD more in touch with reality.

The caregiver's role is a constantly changing one. At each stage or phase of the disease, the care recipient has different needs. The importance of compassionate caregiving and maintaining the person's dignity needs to be constant from diagnosis to death.

Now let's shift our attention from the disease process and its effects on the person with AD, to the caregiver, and see how each stage calls for special action on their part.

Each stage of the illness brings its own special care problems. In the **earlier stages**, the main problems may be forgetfulness and impairment of learning ability. The caregiver's role is to help find ways to maintain the person's ability to act independently, as much as possible. Early on, you must educate yourself about the medical, legal and financial aspects of the disease. Most importantly, now is the time you must prepare yourself for the physical, psychological and emotional demands that caregiving will place on you." An ounce of prevention is worth a pound of cure," and knowing what to expect is half the battle. With careful planning, the caregiver will be able to avert crisis and to appreciate the positive aspects of caregiving, just as a parent lovingly meets the needs of an infant or dependent child. This is the time to arrange for ongoing medical and custodial care and plan for the future.

Safety is a big concern in the **middle stages** of the illness. The memory is failing and judgement is poor. The person may wander or get into things in or around the home that pose a danger. You may have to watch very carefully. During this stage, the job of caregiving may well expand beyond the abilities of any one caregiver. You will need to set up a network of care arrangements to spread out the responsibilities.

In the **final stages**, round-the-clock care will be needed. This is the time you will need to consider placing the person in an appropriate facility. This is a hard choice. Talk about it with people you can trust who know what you are going through -- family, friends, a social worker, the clergy, a doctor, etc. Whenever placement does occur, these people are already aware of the situation and can provide support.

We've covered a lot of territory. Let's summarize.

Just as the person with Alzheimer's Disease goes through a progression of stages, primary caregivers also experience various "stages," but they are not necessarily related to the course of the disease. In fact, the degree of burden perceived by caregivers is related to the person's disruptive behavior and impaired social functioning rather than the degree of dementia. It is essential that you be informed and educated not only about Alzheimer's Disease, but also about how it affects the family. You need to be aware of the stages that you will go through (e.g., burden, grief, etc.) as you care for your loved one(s).

This program was developed to provide caregiver education to rural and/or minority family members caring for a loved one with Alzheimer's Disease or a similar disorder. I hope you are finding this session helpful and will come for each session. We will offer information vital to your particular situations, and the sessions will correspond to the progression of dementia. This means each session will build on the previous one(s). Try to attend every session offered.

AUDIO-VISUAL REINFORCEMENT:

"Something's Wrong" (Unit 1, Part I - in the series, "Alzheimer's 101: The Basics for Caregiving") produced by South Carolina ETV in cooperation with the South Carolina Commission on Aging. Distributed by SC ETV Marketing, Drawer L, 2712 Millwood Ave., Columbia, SC.

"Early Stage into Middle Stage" (Unit 1, Part II - in the series, "Alzheimer's 101: The Basics for Caregiving") produced by South Carolina ETV in cooperation with the South Carolina Commission on Aging. Distributed by SC ETV Marketing, Drawer L, 2712 Millwood Ave., Columbia, SC.

"Middle Stage into Late Stage" (Unit 1, Part III - in the series, "Alzheimer's 101: The Basics for Caregiving") produced by South Carolina ETV in cooperation with the South Carolina Commission on Aging. Distributed by SC ETV Marketing, Drawer L, 2712 Millwood Ave., Columbia, SC.

EXPERIENTIAL LEARNING:

1) Distribute the hand-out at the end of this module to your caregiver participants. Be sure you have an adequate number of copies for each person in attendance. The hand out briefly describes the behavioral signs and symptoms of Alzheimer's Disease as it progresses from the earlier to the middle to the later stages. Ask caregivers to review the list and check off the symptoms which they have noticed. Be sure to explain that the stages overlap and symptoms may be seen at more than one stage. The idea is to give caregivers an idea of approximately which stage of the disease their care recipients have progressed to.

This exercise may be done independently, with caregivers privately noting the symptoms to themselves. On the other hand, you may want to have a discussion about how they deal with certain symptoms. Use your own judgment and decide what your particular workshop participants would prefer.

REFERENCES AND SUGGESTED READINGS:

Alzheimer's 101: The basics of caregiving, learner's guide. (1989). Columbia, SC: South Carolina Commission on Aging and South Carolina ETV.

Alzheimer's Disease and related disorders: A description of the dementias. (1991). Chicago, IL: Alzheimer's Disease and Related Disorders Association.

Arizona Long Term Care Gerontology Center. (1990). Alzheimer's Disease: Pieces of the puzzle (Instructor's Manual). Tucson, AZ: University of Arizona.

Boyd, J. R., Frieden, S., Higley, K. O. & Spencer, P. E. (1989). How to cope with Alzheimer's Disease: Training manual. St. Louis, MO: Alzheimer's Disease and Related Disorders Association - St. Louis Chapter.

Caring for Alzheimer's patients : Caregivers' practical help. (1988). Albany, NY: New York State Office for the Aging.

Family guide for Alzheimer's care in residential settings. Chicago, IL: Alzheimer's Association.

Reisberg, B. (1981). A guide to Alzheimer's Disease for families, spouses, and friends. New York: The Free Press, Macmillan.

Behaviors Often Seen in Alzheimer's Disease

The EARLIER STAGES (The "Forgetfulness Phase")

* Forgets which bills are paid
* Forgets phone numbers that are often dialed
* Forgets what he or she has just been told, and denies forgetfulness
* Gets lost in formerly familiar surroundings
* Has trouble thinking of common words or names
* Hides things, or accuses others of stealing or hiding things
* Has careless appearance or attitude

The MIDDLE STAGES (The "Confusional Phase")

* May dress inappropriately
* Fails to understand written or spoken words
* Continually repeats particular movements, statements, or questions
* Uses words illogically
* Wanders and gets lost easily
* Cannot remember recent experiences/occurrences
* Makes up stories to fill gaps in memory
* May have visual and/or auditory hallucinations
* May be extremely nervous, anxious, worried, or irritable
* Has emotional/behavioral outbursts
* Awakens frequently at night; may get up and wander
* Undresses at inappropriate times or in the wrong places
* May display huge appetite for junk food and other people's food; forgets when last meal was eaten, then gradually loses interest in food; chews or tastes available objects

The LATER STAGES (The "Dependent Phase")

* Is unable to perform activities of daily living
* Is more susceptible to pneumonia, viruses, and skin infections
* Is unable to smile or swallow
* Has limited ability to communicate
* No longer recognizes family members
* Cannot feed self
* Is unaware of environment
* Is usually bed-bound
* Believes place where he is residing is not his home or where he should be
* May groan, scream, or make grunting sounds

Module 2: Caring for the Caregiver

GOAL: To help caregivers recognize the physical/emotional symptoms of caregiver burden and empower them to manage the stress of caregiving effectively.

RATIONALE: When caregivers are aware of their own needs, feelings, and reactions to caregiving, they are better able to cope with the physical and emotional demands placed on them. They need to take good care of themselves, so that they can continue to provide quality care for their loved ones.

EDUCATIONAL OBJECTIVES: At the end of this module, caregivers should be able to:

1) Define caregiver burden and list the factors which influence it;
2) List the caregiver's four essential responsibilities;
3) Describe the three major roles of the effective caregiver;
4) List the kinds of stressors that caregivers experience;
5) Recognize the physical symptoms of caregiver burden or strain;
6) List the kinds of emotional reactions to caregiver burden or strain;
7) Explain the three major components of caregiver "burnout"; and
8) List the danger signals caregivers should look for.

MINI-LECTURE:

Dedicated caregivers know how important and valuable they are to the well-being of their care recipients. Caregiving puts a great strain on the body, mind, and spirit. The physical, financial, and emotional stress of caring for a disabled elderly family member is sometimes called "caregiver burden" or "caregiver strain." Caregiver burden can compromise the caregiver's ability to continue providing care over a long period of time. Many factors contribute to caregiver burden. These include:

1) The care recipient's level of physical, cognitive, and social impairment;
   - *More impaired individuals require more "patient" caregivers.*
2) The quality of the relationship between the caregiver and care recipient;
   - *It is less stressful to care for someone you get along with.*
3) The types of care provided;
   - *Personal care (such as bathing, toileting, etc.) may be the most stressful.*
4) The lack of satisfactory assistance with caregiving; and
   - *It is easier to manage when the caregiving responsibility is shared.*
5) The extent to which the caregiver's personal and social life is disrupted.

- *When caregivers no longer have time for themselves, they are more susceptible to stress*

Dr. Steven Zarit has focused his research and practice on caregiver burden for more than a decade. He maintains that caregiver strain is fundamentally different from other kinds of stress (Kent, 1992). Dealing with dementia requires unique coping strategies because the stressful situation is exceptional. It is difficult to realize that we are all potential care recipients. Disease and dysfunction are often random occurrences which can strike anyone any time. Within every caregiver there is an ongoing conflict between feelings of compassionate concern and fear or resentment. This is especially true if the condition is long-term and progressive, as in dementia. As their conditions worsen and dependence increases, care recipients and their caregivers feel more helpless and frustrated. Care recipients may have negative feelings about their caregivers, as well. Instead of being grateful for the care they receive, they may be angry or hostile that they have lost their former degree of independence and freedom.

The onset of irreversible dementia is especially frightening since there is little hope that functional losses may be regained. Caregivers need to try to avoid confrontations whenever possible (see Caregiver Lesson Plan on Managing Episodes of Aggressive or Hostile Behavior). This often means accepting emotional outbursts with quiet resignation. It is also important to preserve the care recipient's sense of value and dignity (see the Caregiver Lesson Plan on Compassionate Caregiving). One way to do this is to allow the care recipient to pay back the caregiver's kindness in some way. Although this may not be practical in the later stages of dementia, creating an opportunity for the care recipient to return the favor can help maintain self esteem. This may be especially important for rural elders who have lived by the "norm of reciprocity" and are used to exchanging favors as a way of life (see Chapter 3: Special Considerations for Trainers of Rural Caregivers).

Caregivers should learn to take good care of themselves and improve their own ability to provide quality care for their loved ones. Don't neglect yourself! Many caregivers focus total attention on their loved ones, whose needs they feel have become "more important" than their own. Just like the care recipient, you need support, understanding, and encouragement. Your needs do not stop when a loved one becomes ill. It's important to set realistic goals and limitations on your responsibilities. The basic goal of caregiving is to ensure the comfort and safety of the care recipient while promoting emotional stability and self-esteem. The caregiver has four essential responsibilities. They are:

(1) Learn as much as possible about the disease.

- Families often express regret about not learning more about Alzheimer's and dementia right from the start. The family needs to explore the legal and financial implications as soon as a diagnosis is made. Knowledge of the disease and how to manage the day-to-day activities of their loved one are the caregiver's most important tools.

(2) Find knowledgeable health care professionals willing to treat both the recipient and the caregiver.
- As many as 65% of family caregivers experience symptoms of depression. Others deal with an extraordinary amount of anxiety or worry excessively. For these caregivers, help from professionals who are well versed with Alzheimer's Disease is advisable. Denying how you feel (whether to "protect the care recipient," to "put up a good front" for family and friends, or because you "don't have the time or energy" to think about yourself) only makes matters worse. You are not "crazy" if you seek the help of a professional. Getting help for yourself may give you more energy to cope with the task of caregiving. Someone who knows what AD does to the care recipient and what it does to the family will be better able to provide the help needed.

(3) Change the person's surroundings as needed and establish a daily routine.
- (see Caregiver Lesson Plans on Safety and Environmental Adaptations and Managing the Daily Routine)

(4) Obtain help and respite services.
- (see Caregiver Lesson Plan on Formal Supports and Resources)

Caregivers fill many roles and continually learn new skills. They supervise where their care recipients go and what they do. A caregiver may serve as a nurse, advocate, and guardian, making decisions which will affect their own and their care recipients' futures. Effective caregivers have three major roles: the manager, the learner, and the observer. The caregiver who is aware of these roles will be better prepared to meet the challenges of caregiving.

The Caregiver as Manager

The caregiver manages the innumerable tasks required to take good care of someone who is dependent on their skills and efforts. A good manager relates well to others, coordinates and supervises activities, and delegates tasks when appropriate. A good care manager masters all these skills. You must develop a good relationship with the care recipient and everyone else who is involved in the caregiving process. Try to find dentists, lawyers, counselors, etc. who are knowledgeable about Alzheimer's Disease and can be flexible about appointments, home visits, etc. Because you are the major link between the care recipient and everyone else, you have to keep others informed of the person's well-being and let them know when you could use their help. Do as much long term planning as you can. It is up to you to make plans for future care. Talk to legal and financial experts at the earliest opportunity (see the Caregiver Lesson Plan on Legal and Financial Issues). To provide the best care, organize a network of helpers. Although you may simply delegate responsibility to family and friends at first, later it is important to find other kinds of home-based, community-based, or institutional help. Because your role as a care manager is of crucial importance, you must take good care of yourself.

The Caregiver as Learner

By learning the limitations of the person they care for, a caregiver will be better prepared to deal with situations which arise. Some behaviors are due to damage in the brain and cannot be controlled. Brain damage causes people to see, hear, feel, and think differently. This causes them to react in ways that seem wrong or cause pain. Wise caregivers learn the difference between problems they can and cannot solve. They learn not to take it personally when their care recipients strike out at them. Caregivers must learn to respond calmly and provide reassurance. Responding with kindness may be the best way to cope at times. Except for rare occasions, it is difficult to teach a person with dementia how to act. There are moments when "the fog lifts," and the person with AD seems almost normal again. These periods of lucidity are sometimes called "the teachable moment" (Hall, Schlueter, & Colvin, 1993). Caregivers should learn to recognize and take advantage of these opportunities. Most of the time, it is the caregiver who is the learner. Learn to devise your own "tricks of the trade." The clever caregiver invents ways to help the person with dementia be independent (see Caregiver Lesson Plans on Managing the Daily Routine and Safety and Environmental Adaptations).

The Caregiver as Observer

Effective caregiving involves careful observation. By watching the behavior of their care recipients, caregivers can learn a great deal of information. The knowledge that is obtained can be used to explain to others what is happening to the individual. Active information gathering can help with the other important aspect of caregiving, i.e. problem solving. Caregivers can become experts on how their care recipients react to different situations, what calms them, what gets their attention, what makes them happy, and what keeps them occupied. Doctors often rely on caregivers for information about their patients' physical and emotional health. The more observant you are, the better able you will be to give thorough and correct information to the doctor. Observe yourself! Try to see yourself the way your care recipient does. This knowledge will help you avoid triggering emotional outbursts (see Caregiver Lesson Plan on Managing Episodes of Aggressive or Hostile Behavior). Pay attention to your own health and happiness so that you can avoid fatigue and stress.

As the person's condition changes, the caregiving role changes in response. Family caregivers are subject to a whole host of stressors (or sources of stress) which come from their unique duties and experiences in the different roles they assume. These include:

1) Changes in the roles filled by the person with AD and the extent to which they can continue to fulfill their responsibilities of parent, spouse, lover, friend, worker, etc.;

2) Changes in the caregiver's role as work, social and leisure activities are given up to meet the demands of caregiving;

3) Being unable to attend to personal needs because so much time is devoted to caring for the person with AD;

4) Increasing pressure to stay in control, or at least appear to be "on top of the situation," i.e., constantly feeling the need to present a "brave front" to outsiders;

5) Loss of personal freedom and privacy;

6) Having trouble finding outside services or being transferred from agency to agency by providers who seem uncaring; and

7) Financial problems due to limited programs/insurance to cover long-term illness or loss of the care recipient's and/or the caregiver's salary.

Caregiving is physically demanding, and prolonged periods of stress can cause illness. Caregivers can "work themselves into an early grave" from sheer physical exhaustion. Many people with Alzheimer's actually outlive their caregivers, especially if the caregivers are older themselves. Caregivers need to pay attention to their own physical well-being. It's as important for you as it is for the person you care for to eat properly, exercise, and get enough sleep. Stress has been linked to many physical ailments. These include headaches, ulcers, colitis, asthma, circulatory problems, gastrointestinal disorders, and compromised immune system functioning. You should be aware of any physical reactions you may have to the stress of caregiving. Changes in appetite or weight, increased fatigue, stomach ache, heart burn, high blood pressure, backaches, diarrhea, constipation, and joint or muscle pain could be an indication that stress is taking its toll. Stress can also cause nightmares and frequent accidents. Seek the advice of a physician. Ask for suggestions on how to keep up your physical strength.

Caregiving can also be emotionally exhausting. There are many emotional reactions to the responsibilities of caregiving. Recognizing these feelings is the first step in combatting the effects of caregiver burden. These feelings may include the following:

> Anger: Sometimes it may seem that those with AD are intentionally behaving badly. Caregivers may take it personally when care recipients vent their frustration and irritability by striking out. The natural reaction of caregivers is anger and hostility. When angry feelings surface, caregivers should take a "time out" and analyze the situation. Most of the time, misbehavior is simply a consequence of the disease and is not intended to irritate the caregiver. A "cool head" and a mature understanding are the caregivers' best defense against angry flare-ups.
>
> Helplessness: Sometimes caregivers feel that they simply can't do enough to help their loved ones. In some ways, persons with AD can't be helped. The course of the disease cannot be halted. Although they may reach a plateau and not show significant functional or cognitive declines for extended periods of time, deterioration is progressive. Caregivers can combat their feelings of helplessness by learning as much as they can about the disease and meeting the challenges of caregiving. Caregivers find that they have a wealth of personal experiences and resources that they can draw from to overcome feelings of helplessness. There are many ways to improve the situation, all of which start with a positive attitude. (See Caregiver Lesson Plan on Managing Resistive Behavior Associated with ADLs).
>
> Frustration: Caregiving can be a thankless job. Devoting care and patience to people who may not be able to express their appreciation can be frustrating. Sometimes caregivers must be satisfied just knowing that they are doing the best job they can.
>
> Embarrassment: When their loved ones behave in socially unacceptable ways, caregivers can be embarrassed. If such an incident occurs in a public place, it can be a humiliating experience. Sometimes, these behaviors can be changed (See Caregiver Lesson Plan on Managing Episodes of

Aggressive or Hostile Behavior). It's important to keep things in perspective. Caregivers should realize that although social embarrassment is unfortunate and uncomfortable, there are really more important difficulties to deal with. If you take a different view of the situation, some embarrassing episodes can be regarded as funny. It all depends on how you look at it!

Guilt: Caregivers may experience guilt when they occasionally put their own needs before the needs of their loved ones. They must realize that devoting time to their own well-being will ultimately benefit their care recipients. Caregivers can feel guilty for any number of reasons. They may feel regret about the way they treated their loved ones in the past, or because they feel resentment about having to provide care, or that they sometimes lose their tempers. The caregiving situation is full of opportunities to feel guilty! It's important to recognize feelings of guilt and then get beyond them. Don't become a martyr! Caregivers should realize that what is in the past cannot be changed. Instead of continually trying to make amends for something that has already happened, it's best to move on and make decisions based on what is important now.

Grief: The extended nature of Alzheimer's disease or other irreversible dementias results in prolonged grieving over the loss of loved ones as they used to be. There comes a time when your loved one is no longer the person you once knew. Accepting this fact is in some ways like saying goodbye to a loved one who is deceased. Grief is one of the most difficult human emotions to cope with. Often, individual and family counseling or sharing feelings in a support group can be helpful. Caregivers owe it to themselves and to their care recipients to find a way to work through the shadow of grief. (See Caregivers Lesson Plan on The Grieving Process).

Depression: Mild depression is not an uncommon reaction when a loved one is first diagnosed. A period of adjustment is required to accept fully the implications of what is to come. Although caregivers can discover ways of dealing with the sadness they feel, nothing will change the situation that caused depression in the first place. Finding a way to accept what has happened and discovering ways that ease the pain are the caregiver's first responsibilities. It's important also to be aware if depression seems to go beyond mere sadness or discouragement. When depression begins to interfere with effective functioning, it's time to seek professional help.

Worry: Each person has his or her own way of coping with worries. Some worrying is unavoidable. Sometimes it can lead to creative problem-solving. The trick is to know the difference between thinking about difficulties that can be overcome and needlessly fretting over things that can never be changed. For some people, imagining the worst thing possible can be helpful. Once you have done that, you begin to realize that the most likely consequences may not be as bad as you feared. Like depression, it's important to notice when worry is taking a toll on healthy functioning.

Isolation: Some caregivers feel that they are totally alone in facing their difficulties. This can be especially true of spouses. When the person with whom you shared all of your problems, becomes the problem, the world can feel like a lonely place. It may seem like there is nowhere to go for help and you are the only person who has ever had to cope with your burden. Nothing is further from the truth! Your local chapter of the Alzheimer's Association is there to stand by you. The staff and volunteers are committed to helping families find the services they need. Caregiver support groups have been organized so that those who deal with similar difficulties can share their experiences, feelings, and methods of coping.

All these emotional reactions are appropriate and understandable. There is no "right" way to deal with the range of emotions experienced during the course of dementia. No matter what feelings caregivers have, sharing them with sympathetic others who understand can be helpful. Caregivers have the right to decide for themselves when, where, and whether they want to express their feelings. Some people prefer to sort out their feelings alone. What is essential is that caregivers recognize and understand their feelings so that they can make informed decisions. Unacknowledged emotions can affect decision-making processes and result in poor judgment. They can also lead to psychosomatic problems and stress-related illnesses.

"Burnout" occurs when caregivers have neglected their own health, repressed their emotions, and can no longer effectively care for their loved one with dementia. They have become emotionally and physically exhausted. Burnout can be described as no feeling at all. Care is provided without any apparent emotional reaction. The caregiver simply "goes through the motions" and performs their tasks without any spontaneity or enthusiasm. Burnout is a complex phenomenon. There are **three major components** of burnout: **emotional exhaustion, reduced personal accomplishments, and depersonalization.**

1) Emotional exhaustion occurs when caregivers have used up all of their emotional resources. There is a virtual inability to feel happy or sad. There is only a feeling that one has nothing left to give.

2) Reduced personal accomplishments cause caregivers to have a devalued sense of themselves. They feel that they have no lives of their own beyond caregiving. This is especially difficult when caregivers feel helpless and frustrated. Some caregivers feel that their only purpose in life is to provide care, but they don't think that they can really help their loved ones or make a difference. They regard their caregiving activities as a meaningless "drop in the bucket" because the prognosis is so poor and their care recipients don't ever get better. These individuals are prime candidates for suffering burnout.

3) Depersonalization is the development of a negative and insensitive attitude about the care recipient. This is the most dangerous aspect of burden because it can result in unintentional abuse or neglect.

Burnout can be characterized by the "mea culpa syndrome." Although caregivers realize that their stress is a consequence of the caregiving situation, they may still tend to blame themselves. They believe that they should be able to handle the stress no matter how overwhelming it may be. When they notice signs of stress, they take it as a sign of personal weakness and failure. Very often they suffer from a loss of self-esteem and may become quite depressed.

On the other hand, when burnout occurs, caregivers may blame their care recipients. This negatively affects their feelings for the ones they care for, and causes them to create an emotional distance from them. No matter how much love or respect caregivers feel for their care recipients, it is easy to be critical and speak in a negative way about them. Eventually caregivers may become indifferent and callous. In some ways this is a normal human reaction when care recipients are unappreciative or hostile. Caregivers respond by engaging in counter-aggressive behavior or depersonalization without regard for the care recipient's dignity and feelings. This "tit for tat" reaction may be an unconscious attempt to cope with feelings of grief. Because caregivers care too much, they end up caring too little.

When caregivers experience burnout, there is a danger that their care recipients may suffer. Neglect by a caregiver is the most frequent type of maltreatment of older and incapacitated adults according to Adult Protective Services Program at the Virginia Department of Social Services.* Forty-three percent of all substantiated reports of maltreatment involve neglect by a person who is responsible for the care of an incapacitated adult.

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* Special thanks to Joy Duke, Adult Protective Services, Virginia Department of Social Services for statistical data and information on unintentional abuse and neglect.

Sometimes the incapacitated adult is neglected because the caregiver is unwilling to do those things that must be done to assure safety and well-being (see Caregiver Lesson Plan on Safety and Environmental Adaptations). Sometimes the neglect is spiteful or malicious with the intent to cause harm to the incapacitated adult. This can happen when caregivers have unresolved feelings of anger and frustration. Frequently, however, the neglect is unintentional and without hatred. Many caregivers want to provide the best possible care and devote a great deal of time and effort to the job. Yet, they lack the knowledge and skills required. A caregiver who has received no special training for the job may not have the information needed about basic caregiving procedures. For example, caregivers need to be aware that skin will break down if a person who is confined to bed or wheelchair is not turned or moved regularly. As another example, caregivers who don't know that medication dosages for older people are generally smaller than for younger adults may unintentionally over-medicate their care recipients. Caregiver training programs (like this one) which provide specific instruction on how to provide care, are the best way to prevent this kind of unintentional abuse and neglect.

Instances of unintentional abuse and neglect are more likely to occur when caregivers are "burned-out" or dealing with extreme levels of stress. It's important that they monitor themselves and be on the look-out for the danger signals. These signs suggest it's time to seek assistance from a member of the clergy, a professional psychologist, a local support group, or a service agency.

AUDIO-VISUAL REINFORCEMENT:

"Stress and the Family Caregiver" (Unit 6, Part I - in the series, "Alzheimer's 101: The Basics for Caregiving") produced by South Carolina ETV in cooperation with the South Carolina Commission on Aging. Distributed by SC ETV Marketing, Drawer L, 2712 Millwood Ave., Columbia, SC.

"Look for the Moments" (Unit 6, Part III - in the series, "Alzheimer's 101: The Basics for Caregiving) produced by South Carolina ETV in cooperation with the South Carolina Commission on Aging. Distributed by SC ETV Marketing, Drawer L, 2712 Millwood Ave., Columbia, SC.

"Critical Challenges for Caregivers" (video in the series, "Aging: Bridging the Gap in Rural Health Care", V0054) produced and distributed by the Northwest Geriatric Education Center, 1910 Fairview Avenue E., #203, Seattle, WA 98102 (206) 685-7478.

"Time to Care" produced by Wing Productions. Distributed by the New York State Office for the Aging, 2 Empire State Plaza, Albany, NY 12223-0001 (518) 474-8388.

EXPERIENTIAL LEARNING:

1) At the end of this module is a list of warning signals that caregivers should watch out for. The hand-out is essential for the experiential learning exercise. Prior to the workshop make copies of the hand-out for each caregiver expected to attend. Make extra copies for "drop in" caregivers.

The following exercise is designed to change caregivers' behavior from helplessness to enjoyment through skill building (i.e. recognizing and responding appropriately to danger signals of burn-out). Ask caregivers to review the danger signals to see if any of the signs of caregiver burnout apply to them personally. Give them time to review the list carefully. After it appears that everyone has had a chance to examine the material, explore each danger signal one by one. For each item listed ask the group what could have been done in the first place (if anything), so that the problem which triggered the warning sign could have been prevented or avoided.

The idea is to have caregivers devise solutions to common problems, dilemmas and feelings that they all have experienced or may experience in the future. Facilitate the discussion by drawing from the information provided in the mini-lecture you have just delivered. This will help you to make your points and will consolidate the information for the caregivers. The goal is empowerment! Through this discussion, caregivers should begin to realize that there are things that they can do to lessen their sense of burden.

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DANGER SIGNALS THAT SAY WARNING: CAREGIVER HELP NEEDED

When is it okay to cry "Uncle"? To say, "I can't give any more unless I get some help"? Many caregivers would rather trudge on under unbearable conditions than to admit such "failure." Their own health begins to suffer, and eventually they themselves need care. Some simply don't realize they're taking on too much until it's too late. If you notice any of the following danger signals, you are probably approaching role overload and should seek assistance from a local support group or self-help agency.

1) Your caregiving duties are interfering with your work and social life to an unacceptable degree.

2) You feel you're the only person in the world enduring this.

3) You no longer have any time or place to be alone for even a brief time.

4) No matter what you do, it isn't enough.

5) Family relationships are breaking down because of the caregiving pressures.

6) You realize you're all alone -- and doing it all -- because you've shut out everyone who's offered to help.

7) You refuse to think of yourself because "that would be selfish" (even though you're unselfish 99% of the time).

8) Your coping methods have become destructive: you're overeating or undereating, abusing drugs or alcohol, or taking it out on your relative.

9) Your relative's condition is worsening, despite your best efforts.

10) There are no more happy times. Loving and care have given way to exhaustion and resentment, and you no longer feel good about yourself or take pride in what you're doing.

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Module 3: Coping with Caregiver Stress

GOAL: To empower caregivers to manage the stress of caregiving by teaching effective tools and techniques for coping.

RATIONALE: When caregivers know how to manage stress effectively, they can take better care of themselves while also providing better care for their loved ones.

EDUCATIONAL OBJECTIVES: At the end of this module, caregivers should be able to:

1) Discuss five ways they can take care of themselves.
2) List six ways to prevent caregiver stress.
3) Define stress and distinguish between "eustress" and "distress."
4) Recognize signs of the "fight or flight" response.
5) List some of the symptoms of stress.
6) Describe the benefits of practicing progressive relaxation, visualization or guided imagery, and deep abdominal breathing

MINI-LECTURE:

Caregiver burden was discussed in the previous lesson. We learned what it is and how important it is to avoid caregiver burnout. The stress that caregivers endure is probably greatest during the middle stages of dementia. Yet, caregiver stress begins even before a diagnosis is given. It is stressful to wonder whether someone you love may have Alzheimer's Disease. The period of adjustment, once a probable diagnosis of irreversible dementia is given, is also quite stressful. In the later stages, when 24-hour care seems inevitable, there is also a period of adjustment. The stress experienced when a loved one must be placed in a nursing home can be enormous (see the Caregiver Lesson Plan on 24 Hour Care). The period of mourning once a loved one is deceased also entails significant levels of stress. Grief, which may begin when a diagnosis is given and continues throughout the course of the disease, is probably the greatest challenge to a caregiver's emotional well-being (see the Caregiver Lesson Plan on the Grieving Process).

Because stress can be such an enduring and important influence affecting the relationship between the caregiver and the recipient, it's important to find ways to cope. Knowing about the various methods for dealing with stress, is not the same as actually practicing effective coping strategies. In this lesson you will become aware of many ways to deal with stress, but it is up to you to employ these techniques.

One of the most important things caregivers can do to combat stress is to **be gentle with themselves**. Caregivers didn't create all the problems they face daily, and they can't solve them all either. Although they can't "cure" their loved ones, they can control the way they react and relate to those they care for. There is no shame in admitting we feel helpless at times. Caring and being there are sometimes more important than the caregiving tasks performed.

Even if it is difficult at first, **talking about their stress** can be helpful for many caregivers. On the other hand, some caregivers may prefer to deal with it privately. The important thing is to identify the sources of stress and find ways to cope. Caregivers who would rather not involve others in their difficulties should consider **keeping a diary**. Putting your problems down in writing can be helpful. Instead of keeping everything bottled up inside, a session with pen and paper may serve as a comforting and useful substitute for talking.

Caregivers who want to discuss their problems with others will find many appropriate "sounding boards." Members of the clergy, counselors, psychologists, social workers, doctors, nurses, other family members, and friends can offer a sympathetic ear and perspective in times of trouble. A support group of other caregivers may be the ideal place to discuss feelings and solve problems. The group provides a safe place to "unburden," because everyone there knows what it's like.

There is a difference between "talking things out" and complaining, however. When caregivers discuss their problems with others, it can relieve some of the burden they feel. Explaining the difficult balancing act that caregivers perform, helps others understand what they are going through. It may lead to solutions or better ways of managing different situations. On the other hand, caregivers who continually complain that "they do so much without any support from anyone else," are simply reinforcing the negative stress they feel. It makes the caregivers feel worse, and rather than getting offers of help from others, it may alienate them.

It's much better to **take a positive approach**, encouraging others to "pitch in" and accepting the praise and support they offer. The language caregivers use makes a difference in their attitudes. Saying "I choose," rather than "I should, I ought to, or I have to," conveys a sense of control to themselves, as well as others. Saying "I won't," rather than "I can't," implies a matter of choice, not limitation. It may seem like a small thing, but the way we feel about ourselves can be shaped by the way we say things.

Caregivers can also take care of themselves by **being creative and trying new approaches**. It's helpful to share ideas with other caregivers and be open to alternate ways of doing things. If something isn't working, do something else. If that doesn't help, try yet another method. Problem-solving for caregivers is often a matter of trial and error. In time, the right answer can usually be found.

Spending time alone or with friends and family is a welcome change from continuous caregiving. It's important that caregivers get help with various duties and **seek out respite**, or time away from the caregiving situation. Serious consideration should be given to options such as enrolling the care recipient in an adult day care program, hiring a homecare aide, or asking someone they know to spend a few hours with the person. Caregivers should carefully explain beforehand what the respite care provider can expect from the person with dementia, and how to handle any problems that might arise. When the "surrogate" caregiver has been given thorough instruction, caregivers can feel more confident and enjoy their time away more fully.

Even when long term respite is not practical, caregivers should find someplace to go and **get away from it all**. This "hermit spot" or "quiet hideout" could be a room in the house (e.g., the bathroom) or outside (e.g., under a tree or in a garden). The idea is to find some peace and quiet where interruptions are limited. If possible, caregivers should retreat to this place on a daily basis, just to collect their thoughts. Consider scheduling "withdraw" periods for several times during the week.

Finally caregivers are encouraged to **laugh, play, and stop "to smell the roses along the way."** Although it may seem at times that there is nothing to laugh about, a sense of humor can be the caregiver's saving grace. Continuing to find joy in life and indulging in simple pleasures, will protect caregivers from the destructive influence of stress. Even when life seems filled with fatigue and frustration, it is still possible to experience laughter, love, and joy. Caregivers should remember and reacquaint themselves with the "little things" that used to make them smile or feel good. Laughter is a gift that helps us maintain sanity in the face of hardship and trouble. One person with Alzheimer's in the early stages claims that "the game of Alzheimer's can be fun, if you know how to play it" (McGowin, 1993). There is no reason to feel badly if you find some mistakes amusing. Your loved one may even join in the laughter, even if they aren't sure what is funny.

There are some things that caregivers can do to prevent negative stress in the first place. These are:

1) **Learn as much as possible** about Alzheimer's disease or related dementias. When caregivers know about dementia and can anticipate what will happen, they will be able to manage care more effectively. You can be more tolerant and understanding when you have some basic knowledge of how the disease affects the brain and thinking.

2) **Have realistic expectations**. Caregivers need to admit that they can't fix everything and make it all right again. It is possible to make life easier for your loved ones, however. Persons with dementia may sometimes be able to do more than expected, and at other times, they may not meet their caregivers' expectations. By progressive refinement over time, expectations will become more accurate.

3) **Accept your mistakes**. No one is perfect. The important thing is to learn from your mistakes and go on. Forgive yourself if you become angry or depressed. These reactions are natural.

4) **Identify what causes the most stress** for you and minimize your exposure to those situations. Many situations require compromise. Notice when your stress level is high and try to avoid engaging in those activities.

5) **Accept and enjoy your successes**. Occasionally, step back and reflect on the wonderful work you are doing. You have made a decision that everyone admires and respects. Taking responsibility for another person's care and comfort is regarded as an act of "near-sainthood" by most people. The support and approval towards caregivers is almost universal. Take pride in your accomplishments. Caregiving builds patience and tolerance. Caregivers often find that they have a renewed gratitude for their own health and abilities. They also develop a greater appreciation for the good things in life.

6) **Reward yourself**. Giving yourself regular treats (not necessarily food!) will help maintain a healthy balance in your life. Treasure yourself. You are doing good deeds everyday. By treating yourself to best friends and fun activities you can keep a good outlook on your life.

Different caregivers find different ways of coping with stress. It may take some time to find out what works best, but it's important to discover what is the best method for you. Below are some examples of coping strategies that other caregivers have found for themselves (Ballard & Gwyther, 1990).

> ". . . I go out to my car and listen to gospel music. That always calms me down and helps me see things differently. It gives me strength somehow."

> "I work hard at keeping myself physically and spiritually healthy. That's the only way to do it. This is a hard job!"
>
> "I do a good job. My faith and belief that this is important helps me on those difficult days . . ."

Prayer, faith, and religion are powerful coping methods for some caregivers. Although some caregivers may prefer to draw upon their personal spiritual resources, many religious communities offer support to caregivers and their families. In fact, some faith groups are taking it upon themselves to seek out and minister to those who care for older persons. Whether spiritual guidance and comfort is pursued independently or within the context of an organized faith, it can do much to lessen a caregiver's sense of burden (see Caregiver Lesson Plan on The Caregiver's Spiritual Resources).

Stress is with us all the time. Hans Selye, M.D. has defined stress as "a non-specific response of the body to a demand." Without stress, life would be dull and boring. All mental, emotional and physical activity is accompanied by a certain level of stress. There are really two different kinds of stress. **"Eustress"** is the good kind of stress. It is invigorating and challenging. It has a positive influence on our lives. **"Distress"** is the bad kind of stress. It results when a demand becomes prolonged or frustrating. The term "stress" commonly refers to this bad stress. Caregivers need to recognize the early signs of "distress" and do something about it.

The body responds to stress by going through three stages: **alarm, resistance, and exhaustion.** When an event is interpreted as threatening, the body prepares to either confront or escape the threat. This reaction is called the "fight or flight" response. The pupils of the eye become larger, muscles tense, heart rate and respiration increase, and blood drains from the hands and feet leaving them cold and sweaty. This reaction can occur when a person feels like they have little control over the environment or what they are experiencing. The "fight or flight" response is a common reaction in an emergency. It can also occur when we are on the verge of losing our tempers or when we are emotionally frustrated. When this "alarm" reaction continues without being alleviated or when still further stress is added, the stage of "exhaustion" is reached. This is the point where serious health problems develop. "Resistance" precedes "exhaustion" as an intermediary stage occurring after the "alarm" reaction.

Note to the trainer: *Dr. Selye has developed a check list of symptoms that indicate stress. Read the list of symptoms to caregivers. Have them ask themselves how* *often they experience any of these symptoms. Once you have completed the list, suggest that if they answered often or always to any of the symptoms listed, they could benefit from practicing stress reduction exercises.*

1) Irritability or depressed mood
2) Pounding heart
3) Unusually dry mouth or throat
4) Want to cry, run, or hide
5) Can't concentrate
6) Tired
7) Feel blah
8) Keyed up
9) Easily startled
10) Can't sit still
11) Grind teeth
12) Change in appetite
13) Nightmares
14) Oily skin
15) Flushed face
16) Frequent urination
17) Cold hands
18) Burping
19) Face feels hot
20) Tight stomach muscles
21) Sweaty hands
22) Gassiness
23) Acid stomach (heartburn)
24) Shallow, rapid breathing
25) Cold feet
26) Diarrhea
27) Heart palpitations
28) Shortness of breath
29) Shaky hands

Note to the trainer: *To deal with stress, caregivers must be tuned into their own bodies and aware of their reactions to stress. Experiential exercises 1 & 2 at the end of this mini-lecture will help caregivers become more aware of themselves. After reviewing the exercises, decide for yourself whether the caregivers in your workshop would be comfortable engaging in the exercise as a group. If you aren't sure, explain the exercises and ask the caregivers themselves whether they would like to participate. If you prefer not to use these exercises, simply suggest that caregivers practice them on their own. Ask them also to try and pay more attention to how they react to stressful situations. Tell them to notice the cues their bodies give them when they are stressed. Instruct them to note which muscles become tense when they are in difficult situations (e.g., neck, shoulder, lower back, face, abdomen, etc.).*

When people are especially hassled, there is a temptation to think that there is no time to relax or otherwise take care of themselves. This is a self-defeating trap. It's important to take care of yourself on a daily basis. One way is with physical exercise. When you are nervous, angry, or upset, try running, walking, playing tennis, or working in your garden. A physical work-out will relieve that "up tight" feeling and help you relax.

One of the best ways to relieve tension is through a technique called "progressive relaxation." This technique was developed and published by Edmond Jacobson in 1929. He believed that tense muscles are the body's response to anxiety-provoking thoughts. The tense muscles, then, increase feelings of anxiety. Progressive relaxation calms the body down. Heart rate, blood pressure, perspiration, and respiration all decrease when the technique is practiced correctly. Over the years, progressive relaxation has been used to treat a number of maladies including: insomnia, depression, fatigue, irritable bowel, mild phobias, and stuttering.

Note to the trainer: *Exercise 3 at the end of this mini-lecture involves participants in progressive relaxation. It can be practiced while lying on the floor or sitting in a chair (preferably with the head supported). Although the exercise is simple it takes a little time to do correctly. Use your own judgment about how your participants will react to conducting the exercise in a group setting. Although this technique can go a long way in helping caregivers deal with stress, they may prefer to try it in a more private setting. If you aren't sure, explain the technique and ask the caregivers whether they would like to practice it as a group or in private. If anyone seems hesitant, explain the exercise in detail and have them try it on their own. Be sure to have the group members write down the order of the progression (feet, calves & thighs, stomach, chest & back, hands, arms, neck, and face). At the next workshop, ask if anyone tried the technique and whether it was helpful.*

Another technique for dealing with stress is called "visualization" or "guided imagery." Visualization involves holding specific images or pictures in the mind. A beautiful or relaxing scene is imagined along with the pleasurable sensations involved. This technique provides a quiet moment of peace and tranquility when you can't physically get away. It allows you to get out of the turmoil of a stressful situation and experience a short refreshing "vacation."

Note to the trainer: *Exercise 4 at the end of this mini-lecture is a guided imagery or visualization exercise. The procedure is relatively harmless and should not cause discomfort for your participants. Since the exercise is short and simple caregivers should be encouraged to practice it anytime they feel overwhelmed or in danger of losing their tempers.*

When people have emotional experiences, their breathing patterns change. By consciously changing your breathing, you can alter your emotions. Correct breathing is **not** from the chest. Abdominal breathing is the most natural. The aging process and normal breathing habits may cause a 20% reduction in oxygen blood levels. Poor breathing decreases our energy and negatively affects mental alertness.

Breathing exercises can help prevent the stiffness in the rib cage and surrounding muscles that come with aging. Stiff and weak muscles result in rapid, shallow breathing. Improper breathing can prevent fresh oxygen from reaching the blood stream. It can also lead to respiratory distress, sluggishness, or heart disease.

Deep abdominal breathing can aid in relaxation and stress management. It is a simple way to modify your physical state to achieve psychological benefits. Observing your breathing pattern and consciously controlling the way you breathe can help you deal with stressful experiences.

Note to the trainer: *Exercise 5 at the end of this mini-lecture outlines the procedure for deep abdominal breathing for relaxation. It takes about 10 minutes and can be practiced while sitting, standing, or lying down. This exercise should not cause embarrassment or feelings of discomfort among any of your workshop participants. Even if none of the other exercises are practiced as a group, this one is recommended.*

Progressive relaxation, visualization or guided imagery, and deep abdominal breathing can all be helpful to caregivers who are trying to manage stress. In this module you have learned some helpful tips on how to take care of yourself to prevent stress, how to recognize stress when it occurs, and how to deal with it. It is one thing to have knowledge and another thing to use it. Caregivers have a responsibility to themselves and to their loved ones to discover and employ the coping strategies that work best for them.

AUDIO-VISUAL REINFORCEMENT:

"Stress and the Family Caregiver" (Unit 6, Part I - in the series, "Alzheimer's 101: The Basics for Caregiving) produced by South Carolina ETV in cooperation with the South Carolina Commission on Aging. Distributed by SC ETV Marketing, Drawer L, 2712 Millwood Ave., Columbia, SC.

"The Problem Solving Method" (1st video in the series, "Improving Caregiving Skills) produced by the University of Southern California, Ethel Percy Andrus Gerontology Center. Distributed by the Alzheimer's Disease Education & Referral Center, P. O. Box 8250, Silver Spring, MD 20907-8250 (800/438-4380).

"The Stress Reduction Method" (2nd video in the series, "Improving Caregiving Skills) produced by the University of Southern California, Ethel Percy Andrus Gerontology Center. Distributed by the Alzheimer's Disease Education & Referral Center, P. O. Box 8250, Silver Spring, MD 20907-8250 (800/438-4380).

EXPERIENTIAL LEARNING:

Exercise 1: Building Self Awareness (adapted from Bane & Halpert, 1986)

This exercise is very easy to do almost anywhere in just a few minutes. The mental break is refreshing. Ask the group to sit in a relaxed position with their eyes closed. Give them a minute or two to settle down and then say:

1) "Focus attention on what is going on around you." Offer examples of what you are perceiving. For example, "I am aware of cars passing by, wind blowing, birds chirping, and a saw buzzing." Ask the group for their own perceptions. Remind them to keep their eyes closed. After you have received their response, say:

2) "Now shift attention to your own body and your physical sensations." Offer examples of what you are perceiving. For example, "I am aware of my stomach gurgling, tension in my shoulders, and my legs aching." Ask the group for their own perceptions. After you have received their response, say:

3) "Move awareness back and forth between what is going on around you and what is going on inside you." The trainer should then offer examples of shifting attention based on their perceptions. For example, "I smell cookies baking. I feel my thighs pressed against the chair. My shoulders are tense. I hear traffic sounds." Ask someone in the group to verbalize their perceptions as they shift their attention from what is going on around them and what is going on inside them.

Conclude the exercise by asking the group to open their eyes. Explain that this exercise will enhance their appreciation of inner and outer states of being. That is, it demonstrates the difference between the inner and outer worlds. It helps to focus attention on what is being experienced in times of stress. Caregivers should be encouraged to practice this exercise on their own.

Exercise 2: Body Awareness (adapted from Bane & Halpert, 1986)

This exercise promotes body awareness and helps identify areas of tension. Explain that you will be asking a series of questions to help participants become more aware of their bodies. Tell them that they should ask themselves these questions silently without voicing the answers. Let them know that when the exercise is concluded, individual group members will have a chance to discuss their experiences.

1) Ask participants to lie on the floor on their backs with their legs a few inches apart and their arms a few inches from their sides.
2) Ask them to make sure they are comfortable. They may need to shift their bodies around. Sometimes it is helpful to put pillows under the neck and knees.
3) Instruct participants to close their eyes and focus on their breathing. It should be natural with moderately shallow slow relaxed breaths.
4) Tell them to feel the air moving into and out of their lungs.
5) Now ask them to focus on their body as a whole.
6) Ask them to notice which parts of their body come to their attention first.
7) Ask them which parts of their bodies they are less aware of.
8) Ask if they notice a difference between the right and left sides of their bodies.
9) Ask if they feel any physical discomfort.
10) Tell them to describe the discomfort silently to themselves in detail and be aware of what happens to the discomfort. Does it become more or less pronounced?
11) Tell them to let their bodies do what it wants to do.
12) Have participants continue to notice their breathing and bodily sensations for a few minutes in silence.

Conclude the exercise by having participants open their eyes and sit up. Ask them what they noticed about their bodies. Ask them why they are more aware of some parts of their bodies than they are of others. Ask them if they felt a difference between the right and left sides of their bodies. Ask what happened to physical discomfort when they focused on it and described it in detail.

Exercise 3: Progressive Relaxation
(adapted from Alzheimer's Disease: Pieces of the Puzzle, 1990
and Bane & Halpert, 1986)

In progressive relaxation, each muscle or muscle group is tensed for five seconds and then relaxed for 20 seconds. The procedure is more effective if it is repeated at least once. At first only partial relaxation may occur, but after the technique is practiced for a while, the whole body will learn to relax in a matter of minutes.

CAUTION: DO NOT tense the neck, back, toes, and feet too tightly. Excessive tensing of these may result in muscle cramping.

Trainers should instruct participants as follows:

1. Sit in a comfortable chair with your feet flat on the floor or lie down on your back. Close your eyes. Let your breathing gradually become slower and deeper. Relax. Focus on your breathing. If other thoughts come to mind, simply let them go by. (Trainer pauses for a silent count of 20).

2. Focus your mind on your feet. Gently tense the muscles in your feet. Hold the tension for a count of five. (Trainer silently counts to 5). Release the tension and relax your feet. Focus on that feeling of relaxation in your feet. (Trainer silently counts to 20). REPEAT.

3. Now focus on the muscles in your calves and thighs. Tense these muscles and hold. (Trainer silently counts to 5). Release the tension in your legs. Notice how relaxed your legs feel. (Trainer silently counts to 20). REPEAT.

4. Tense the muscles in your abdomen and hold. (Trainer silently counts to 5). Release the tension and feel your stomach muscles relax. (Trainer silently counts to 20). REPEAT.

5. Tense the muscles in your chest and back. (Trainer silently counts to 5). Now release the tension. (Trainer silently counts to 20). REPEAT.

6. Now clench your fists tightly and hold. (Trainer silently counts to 5). Now relax your hand and fingers. Feel the tension leave your hand and fingers. (Trainer silently counts to 20). REPEAT.

7. Tense your elbows and biceps. Hold them tight. (Trainer silently counts to 5). Release the tension. (Trainer silently counts to 20). REPEAT.

8. Tense the muscles of your neck. Hold the tension. (Trainer silently counts to 5). Let the tension go. (Trainer silently counts to 20). REPEAT.

9. Now focus on your forehead, eyes, cheeks, jaw, and mouth. Tense all these areas and hold. (Trainer silently counts to 5). Let the tension go. (Trainer silently counts to 20). REPEAT.

Your body feels light, serene, and completely relaxed. Enjoy this calm sensation as you breathe slowly and deeply.

Exercise 4: Guided Imagery or Visualization
(adapted from Alzheimer's Disease: Pieces of the Puzzle, 1990
and Bane & Halpert, 1986)

Note to trainers: *Guided imagery or visualization is a technique that can be used as part of progressive relaxation or by itself. If used as a part of progressive relaxation, trainers should skip the first paragraph of instructions below and go directly into the visualization fantasy. Tell participants that they should use the words as a starting point to form their own images if they want. It's important that they use as many senses as they can. They should imagine the sight, sounds, smells, tastes, and touch of the fantasy. This will allow them to fully experience the visualization. Soft, soothing music may be played in the background to enhance the exercise.*

The trainer should instruct participants as follows:

"Take a slow, deep breath. Close your eyes and breathe slowly. Let your stomach rise with each inhale and fall with each exhale. Slowly and methodically scan your body, thinking about each muscle group. Is there any tension in your face and neck? Relax your face and neck. Is there any tension in your shoulders and arms? Relax your shoulders and arms. Is your abdomen tense? Relax the muscles in your abdomen. Is there tension in your legs and feet? Relax your legs and feet. Focus on your breathing. Listen to the sound of each breath as you inhale and exhale.

Now imagine that you are carrying a large bag over your shoulder. This bag is filled with all of your troubles, all of the things on your list 'to do', your concerns, and all of the decisions you have to make. The bag is full of everything that is weighing you down these days. Concentrate on everything that is in that bag and how heavy it is. Feel the weight of the bag on your shoulder. Notice how your body responds to all of that weight. The muscles in your shoulder, arms, and back are carrying that weight.

In your imagination, walk to a favorite spot in your home or yard. It may be a window with a pleasant view, or someplace where you go to be alone like the bedroom or bathroom. While you are standing there, let the bag slip from your shoulder onto the floor. What a feeling of relief! You may feel like taking a good rest now . . . breathe deeply, smile to yourself and enjoy your mental and physical break.

Look into your bag and see if you are carrying things you don't need. If so, take these things out of the bag so it will be lighter for you. Perhaps there is nothing you can take from your bag this time. That's OK. You know what is best for you.

Take another moment to savor the relief of putting your bag of cares down. Promise yourself to return to this place of peace and rest when you need to. Now that you are refreshed, put the bag on your shoulder. It feels lighter now doesn't it? Even if it still contains all of your worries and concerns, you can manage it better, because you took some time to care for yourself as well. Now return to the present, opening your eyes when you are ready."

Exercise 5: Deep Abdominal Breathing for Relaxation
(adapted from South Central Regional Medical Education Center, 1988;
Bane & Halpert, 1986)

Many people breathe from the chest. Abdominal breathing is the proper, more natural way to breathe. When people are very relaxed or asleep, breath is drawn from the lower abdomen. Conscious control of breathing will help maintain a relaxed state and an active mind.

You may find abdominal breathing difficult at first. This is not the way you were taught to breathe. In abdominal breathing your stomach goes out on the inhalation and is sucked in on the exhalation. This is the opposite of the dictum "stomach in, chest out." If you have trouble with the technique, just concentrate on relaxing your body and mind completely. Abdominal breathing is difficult to do when you are tense or anxious. If you imagine that you are falling asleep, it may be easier to breathe this way.

1. Stand in a comfortable position with the feet apart and the knees straight but not locked. Relax your shoulders and let your arms hang loosely by your side.

2. Lay the palms of your hand on your stomach just below the rib cage with your middle fingers just barely touching. This is where your diaphragm is. The diaphragm is a set of muscles between your chest cavity and your abdominal cavity. The diaphragm is pushed down as air is drawn into the lungs. The air is expelled when the diaphragm is pushed up.

3. Exhale as completely as you can through your mouth. As your diaphragm pushes down, your fingertips will separate slightly. Feel your chest collapse, your rib cage contract, and your abdomen fall inward. Simultaneously your upper, middle and lower lungs empty air.

4. Begin to inhale slowly through your nose. As your diaphragm moves upward, feel your belly rise. Your chest, rib-cage, and shoulders should not move at all. Only the abdomen swells, as the lungs fill with air.

5. Keep inhaling until your belly feels full and stretched. Then exhale slowly allowing your belly to fall inward. Empty your lungs of as much air as you can. Contract your abdominal muscles slightly at the end of the exhalation. This will pull your diaphragm up further forcing every last bit of air out.

6. After a short pause, begin the whole cycle again. Close your eyes and practice deep abdominal breathing for about ten cycles. The pace should be slow and natural. Breathe in only when you feel the need, and take in only as much air as is comfortable. Be sure to exhale completely.

7. Before opening your eyes, notice any change in your mental state. Learning control over the mind and body begins by observing the little changes you can produce.

8. After you have practiced abdominal breathing for a few days, try to make a habit of breathing this way. Do it while you are sitting, standing, walking around, and lying down. It is superior to chest breathing in many ways.

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COPING STRATEGIES

(Adapted from Alzheimer's 101: The basics for caregiving, 1989)

By finding effective strategies for alleviating stress caregivers can improve their mental and physical well-being. This, in turn strengthens their ability to provide good care. Complete the following checklist, indicating those coping strategies that you currently practice and those that you don't practice. When you are finished, look over the list and select those strategies which you are not practicing, but would like to try.

	Coping Strategies	**Currently Practice**	**Do Not Practice**
1.	I recognize the sources of stress in my life related to, and beyond, my role as a caregiver.	___	___
2.	I engage in deep relaxation for at least 30 minutes daily.	___	___
3.	I have a place to cry or scream in private when I need it.	___	___
4.	I let family and friends know when I'm in need.	___	___
5.	I fully enjoy at least one experience daily.	___	___
6.	I create my own diversions.	___	___
7.	I have an active hobby that I make time to pursue.	___	___
8.	I maintain my body weight within 10 pounds of what is normal for my height and age.	___	___
9.	I eat three balanced meals daily.	___	___
10.	I exercise for at least 30 minutes three times per week.	___	___
11.	I get sufficient rest and sleep.	___	___

	Coping Strategies	**Currently Practice**	**Do Not Practice**
12.	I take advantage of available respite services: adult day care, homemaker services, etc.	___	___
13.	I receive sound legal and financial advice from a qualified professional who understands the implications of long-term dementing illness.	___	___
14.	I have a good doctor who understands my role as caregiver.	___	___
15.	I participate in a support group, or I see a private counselor who understands dementia and the caregiving process.	___	___
16.	I have a supportive family available.	___	___
17.	I have supportive friends available.	___	___
18.	I have new information about dementia to keep myself up-to-date.	___	___
19.	I try to take one day at a time.	___	___
20.	I accept that I cannot change the person with dementia and I cannot change past difficulties with the individual.	___	___
21.	I try to not overreact to small crises.	___	___
22.	I maintain my sense of humor in and out of my caregiving role.	___	___
23.	I look for the positive moments.	___	___

Now look over your list and select one or two strategies you would like to begin tomorrow. Number these 1 and 2, indicating the most important and second most important strategies to you. After you have successfully integrated these into your routine, return to this list and decide which strategy you would like to try next. Don't put yourself under extra pressure to change all at once! Give yourself the opportunity to be successful with each and don't take on more than you can handle at any given time.

Module 4: Sharing Responsibilities

GOAL: To involve family and friends in the care of a loved one with dementia.

RATIONALE: A caregiver, no matter how well-intentioned, will require help from others at some point. Help is essential to providing the best care and maintaining the caregiver's health and well-being. Caregivers should be encouraged to enlist the aid of family members and friends. By combining their personal expertise and knowledge, helpers can assist the primary caregiver in providing the best care possible.

EDUCATIONAL OBJECTIVES: At the end of this module, caregivers should be able to:

1) List five reasons why family and friends may be reluctant to offer help.
2) Explain the advantages of having others help care for the person with dementia.
3) Describe six roles or functions assumed by family members and how they can influence the caregiving process.
4) Successfully organize a network of mutual caregivers and conduct family meetings.

MINI-LECTURE:

Family and friends should have a major part in caregiving. Too often it falls to one family member (the "primary" caregiver) to provide most of the care. The primary caregiver can always use help from others, especially from family members. Since this help is not always easy to find, it's important to involve other helpers as soon as possible and keep them involved throughout the duration of caregiving.

There are many reasons why the primary caregiver ends up shouldering all of the responsibility. Very often, when others offer little or no help, primary caregivers simply accept the situation, believing that they must "do it all" themselves. More often than not, the care providers themselves are not fully aware of the stress-related effects on their physical and psychological health. Even immediate family members may not see the toll that caregiving is taking on the caregiver.

When family and friends don't offer assistance, it is often because they have misconceptions about the care-giving situation. For instance:

(1) Sometimes other relatives feel that the primary caregiver is doing a fine job alone and doesn't need or want any assistance.

(2) On the other hand, they may fear that they will be taking on too much by offering to help, realizing that caregiving takes a great deal of time and often disrupts day-to-day life.

(3) Others may not feel responsible because they are not as close to the care recipient as the primary caregiver.

(4) People who could help may be afraid that their offer of assistance will insult the caregiver by implying that they aren't doing a very good job.

(5) Sometimes those who would like to help, think that they don't know enough about dementia and Alzheimer's Disease. They may also be frightened by the disease or what they think the person might do. They may even believe it's contagious!

There are distinct advantages to having other family members and friends help with care. It is also good for persons with dementia to spend time with other people. When they have spent time with people other than the caregiver, it is easier to leave them in the care of someone else. When the caregiver needs to have someone else provide respite care (however temporarily), the substitution is more difficult if the impaired person is unaccustomed to being with other people. Having family and friends involved in the caretaking process helps overcome ignorance or fear about the illness. It also enables them to gain an appreciation for what the primary caregiver must deal with.

The caregiver must remember that **others will not offer to help unless they are aware that their assistance is wanted and needed**. The caregiver should clearly explain exactly how they can be of help. Specific requests (such as "I need someone to sit with Mom for a few hours tonight" or "Will you take John to the doctor Tuesday afternoon?") will often get positive responses since the amount of time and effort to be committed is clear.

When family members cooperatively provide care, the primary caregiver feels less burdened or stressed. On the other hand, if family members are available to help but do not or will not, the caregiver's feelings of anxiety, frustration, and resentment may reach critical levels. To change this situation, caregivers must recognize the family dynamics and begin to exert deliberate control. Most family members have particular roles or functions. Caregivers need to make a concerted effort to identify these individuals and incorporate their roles in the process of caregiving. Researchers at the University of Toronto have analyzed the structure of families and found six major roles (Rosenthal & Marshall, 1983). These are:

1) The Kinkeeper: The primary caregiver is called the "kinkeeper." This person is not appointed by the family, but assumes the role voluntarily based on the family's history. The kinkeeper is usually a woman and has provided care before, usually for children in the family. This person is also the one who takes responsibility for keeping the other family members in touch with one another. The kinkeeper typically organizes special events, like birthday parties and family reunions.

2) The Ambassador: Usually there is one person, the "ambassador," who represents the family to the outside world. The ambassador makes sure that someone from the family attends funerals, weddings, and other events involving the extended family or friends. This person could become a liaison linking the family with formal services and resources.

3) The Comforter: This member plays an important socio-emotional role in the family. The Comforter offers advice or comfort to other family members. He/she is the one others turn to when they have problems. This person can be especially supportive of the kinkeeper, helping to encourage the involvement of others in caregiving.

4) The Financial Advisor: The person who fills this role can be an important contributor to the caregiving process. This individual provides advice about financial matters and may also make financial decisions for the family. The kinkeeper may need to work closely with the financial advisor when the expenses associated with caregiving become an issue.

5) The Fence-Sitter: Some families may include someone who plays the role of "fence-sitter." This person is usually not very actively involved and seldom has any input into caregiving decisions. Sometimes, the fence-sitter may add to the kinkeeper's burden by siding with another influential family member who opposes the kinkeeper. Yet, the fence-sitter may have untapped competencies and could serve as a supportive ally of the kinkeeper. It may be worthwhile to cultivate the involvement and

cooperation of the fence-sitter.

6) The Consultant: Like the fence-sitter, the "consultant" does not usually provide on-going care, but may influence the caregiving that is provided. The consultant is well-respected by other family members and may live some distance from the rest of the family. It may be a relative who visits infrequently but disrupts caregiving patterns when they are there. The consultant may be particularly attentive to the care recipient during the visit, but their degree of commitment, contribution, and responsibility is weak. His/her intrusion can negatively affect the relationship between the kinkeeper and the care recipient. Because the consultant is so highly regarded by the rest of the family, the kinkeeper may be unfairly and unfavorably compared. Impressed with the special treatment received from the consultant, however briefly, the care recipient may comment, "Why can't you be more like so-and-so. He treats me wonderfully."

Caregiving families may include many more members and roles than the ones outlined here. By identifying the ways in which families function, and the natural roles assumed by each member, caregivers can more easily involve others in caregiving and delegate responsibility.

One way to involve others in caregiving activities is to hold a family meeting and invite close friends who could help sometimes. Include anyone who may be of assistance (spouses, children, siblings, grandchildren, cousins, etc.). Including the care recipient in the meeting is sometimes a good idea and will help emphasize the need for others to become involved. In addition, the person with AD may feel reassured by the concern shown by others. Hold the meeting at a convenient time and location for those who will attend. The primary caregiver should ask others to make phone calls announcing the meeting, then follow up with written notice of the time, date, and place. Be sure to thank those who agree to attend. Gratitude is the caregiver's most effective "currency," encouraging the involvement of others and making them feel appreciated.

If a "meeting" with an agenda is too formal, invite family members to get together for a pot luck. Explain that afterwards "we'll talk about how to help Mama." Make it clear that the purpose of assembling the family is to focus on sharing the care of the loved one. The primary caregiver should prepare a list of the specific needs (e.g., in-home respite on Tuesday mornings and Wednesday nights, transportation to day care on Monday and Fridays, etc.). WRITE DOWN who agrees to do what on a large calendar. Because the caregiving plan can get complicated, it's essential to have it in writing for everyone's benefit. For example, Sister may provide transportation on Monday, but Brother may do it on Friday.

At the first meeting, explain that the disease is progressive and the need for help will only increase. If possible, the meetings or "get-togethers" should be regularly scheduled (e.g., the second Sunday after church). This is better than calling them on an irregular basis. After the meeting, send a list of the "second Sundays" (specific dates) and places (different family members' houses if appropriate) to everyone.

An "eating meeting" sets the tone for a friendly discussion. In this way, family members will look forward to them, rather than feeling obligated to attend. The meetings also provide an opportunity to celebrate special events -- birthdays, graduations, etc. -- and strengthen family ties. They provide the perfect setting for sharing photographs and videos which the family will cherish later.

A family meeting is an excellent way to share information, feelings, and responsibilities. It can improve communication and cooperation among family members and close friends. The caregiver must make it clear that the care recipient has a disease that will steadily worsen and that care will be needed for a long time. It's important to emphasize that extra efforts in communication, cooperation, and planning are needed.

When organizing the first family meeting, be clear about the purpose of the meeting and the topics to be discussed. List the kinds of assistance needed and who would be the best helper for each task. Provide as much detail as possible so others will know exactly what they will need to do and why. Briefly summarize this information to form an agenda for the meeting.

The caregiver does not necessarily have to preside over the meeting; a family member who is respected or in a position of power may be the best candidate. Designate someone to write down the agreements reached and task assignments. Send copies of these notes to all participants. Generally, there will be a need for continued meetings over the course of the illness. Set the date and time of the next meeting at the initial meeting. If it is practical, draw up a meeting schedule and rotate or alter responsibilities if needed. When mutual caregivers know there is a structure for discussing caregiving issues, they will feel less put upon and more cooperative.

Situations always arise during an illness which require flexibility among mutual caregivers. If someone is unable to fulfill a particular responsibility, immediately notify the others so new plans can be made. It is important to be open about changes that require a reassignment of responsibilities and tasks.

People are often glad to help, when asked, though they might never offer on their own. By organizing a network of mutual caregivers and holding structured family meetings, caregiving responsibilities can be delegated and shared. The primary caregiver will not be over-burdened and better care can be provided to the impaired person for a longer time.

AUDIO-VISUAL REINFORCEMENT:

"Family Caregiver Experiences" (video in the series, "Aging: Bridging the Gap in Rural Health Care," V0054) produced and distributed by the Northwest Geriatric Education Center, 1910 Fairview Avenue E., #203, Seattle, WA 98102 (206) 685-7478.

"Informal Supports: Natural Helping Networks among Ethnic/Minority" (video in the series, "Social and Cultural Aspects of Aging", V0011) produced and distributed by the Northwest Geriatric Education Center, 1910 Fairview Avenue E., #203, Seattle, WA 98102 (206) 685-7478.

"In Care of Families and Their Elders" produced by Lifecycle Productions. Distributed by the Brookdale Center on Aging of Hunter College, 425 East 25th St., New York City 10010.

"Caring, Families Coping with Alzheimer's Disease" produced by Photo Synthesis Productions, Inc. Distributed through your local chapter of the Alzheimer's Association.

"Caring . . . Sharing: The Alzheimer's Caregiver" produced and distributed by Hal Kirn & Associates, 2122 Wallace Street, Philadelphia, PA 19130 (215) 236-3777.

"Who Will Take Care of Grandma?" produced by KIRO-TV. Distributed by the Northwest Geriatric Education Center, 1910 Fairview Avenue E., #203, Seattle, WA 98102 (206) 685-7478.

"What About Mom and Dad?" produced by Frontline. Distributed by PBS Video, 1320 Braddock Place, Alexandria, VA 22315 (800) 344-3337.

"My Mother, My Father" produced by James Vander Bosch. Distributed by Terra Nova Films, Inc., 9848 Winchester Ave., Chicago, IL 60643 (312) 881-8491.

EXPERIENTIAL LEARNING:

1) Give each person the handout entitled "Roles in the Family Structure." Go over the instructions and allow them to work independently if time permits, or to take it home and fill it out. In either case, after the exercise has been completed, ask for suggestions for overcoming the problems created by family members who are "negative forces."

2) Draft an agenda for your family meeting. First list the kinds of assistance which would be helpful to you and then identify family members and close friends who would be the best helpers for each task. Summarize this list into agenda items. Once you have an agenda, the advantages of holding a family meeting should be clear. Plan and conduct your first meeting. You may be surprised at how eager and willing others are to help.

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Silverstone, B. & Hyman, H. K. (1976). You and your aging parent. New York: Pantheon.

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ROLES IN THE FAMILY STRUCTURE

On the diagram below, write in the names of the family members who fill the roles listed. If there are others, fill in their names and give them a title which describes their role in the family. In the column marked "Force" indicate whether the person is a positive force helping the kinkeeper (+), a negative force hindering the kinkeeper (-), or a neutral force neither helping nor hindering the efforts of the kinkeeper (0).

Family Role Name
Force

1) Kinkeeper		
2) Ambassador		
3) Comforter		
4) Fence-Sitter		
5) Consultant		
6) Financial Advisor		
7)		
8)		
9)		

A. Promoting the Effectiveness of Positive Forces

For family members that serve as a positive force, list the ways in which they contribute and help the kinkeeper. Next, develop strategies for increasing their involvement in the caregiving process. Targeting one person at a time, employ the strategies you have devised.

B. Motivating Neutral Forces

For persons identified as a neutral force, note any ways they have been helpful in the past. Next, make a "wish list" of ways in which these individuals could contribute to the caregiving process. Specify caregiving tasks that are particularly suited to these family members based on their abilities or personal characteristics. It's best to ask them to take on a variety of responsibilities initially, and then narrow the list down through negotiation. Emphasize your need for assistance and the seriousness of the matter. Be sure to provide positive feedback for tasks performed. Remind them of their agreements, if necessary.

C. Overcoming Negative Forces

List the problems caused by each person identified as a negative force. (Note: Do not list personal characteristics that you find displeasing or issues that are not related to the caregiving process. You are not interested in venting your anger or changing their personalities. You simply want to specify the ways in which they interfere with your goal of providing the best care possible.) Next, develop strategies for dealing with the problems they create. Meet or talk with them on the phone about the problems you have listed. Ask them to tell you how they see their role and its impact on the caregiving process. Listen carefully to what they say. Try to find a compromise that will solve the problem to everyone's mutual benefit and satisfaction. Try to avoid a major confrontation. Don't anger a potential helper, especially if it is a powerful family member like the Consultant or the Financial Advisor. Consider asking another family member (like the Ambassador or the Comforter) to mediate the discussion. If you can't reach a compromise and the negative forces continue, send your list of problems to the other family members. It is possible that they could persuade the person to be more cooperative. At the very least, the rest of the family will be made aware of your feelings.

Module 5: Legal and Financial Issues

Note to Trainers: This module contains handouts that are integral to this session. Ideally you should have a copies of all documents for each caregiver. Be sure to make enough copies ahead of time.

GOAL: To make caregivers aware of the legal and financial consequences of AD and to determine which legal documents should be executed during the time that the person is still competent to do so.

RATIONAL: The caregiver and his family members need to decide early on in the course of AD which documents pertaining to the management of the person and his medical care should be executed. Such documents must be executed while the person is deemed competent.

EDUCATIONAL OBJECTIVES: At the end of this module, caregivers should be able to:

1) Understand the meaning of the Virginia Advance Medical Directive (i.e., a "Living Will" and/or "Durable Power of Attorney for Health Care."
2) Understand the meaning of the Durable Power of Attorney.
3) Develop a net worth statement of assets and liabilities; and
4) Determine if a will, trust or other such instruments are appropriate.

MINI-LECTURE:

During the earlier stages of AD, families are often consumed with personal issues (e.g., coming to grips with the diagnosis, trying to understand the disease process, helping with instrumental activities of daily living, etc.). They may easily overlook the fact that their family member with AD has a limited time span in which he will be competent to sign legal documents. Some important documents pertain to the management of assets (e.g., durable power of attorney, living trust, etc.). Others (e.g., the living will and durable power of attorney for health care) deal with management of the person.

Guardianship is an adversarial type of proceeding and not usually invoked when a durable power would serve the purpose. Court appointed guardianship is usually invoked when there is no one to care for an individual who is not competent to make decisions. An attorney must be appointed to represent the interests of the allegedly incompetent person. The signed affidavits of two physicians whose examinations suggest that the person is mentally incompetent and unable of managing his affairs are required.

Managing Financial Affairs

With the AD person, there comes a time when routine processes (such as paying bills on time, signing contracts, cashing checks and generally managing finances and/or investments) become difficult. Costly mistakes can occur (e.g., overdue fines) or safety may be jeopardized (e.g., vital utilities may be disconnected for non-payment). Sometimes persons with dementia give away valuable items or are victims of consumer fraud. There are legal ways to protect the person's assets.

BY NO MEANS IS THIS MODULE OFFERING LEGAL OR FINANCIAL ADVICE! Every situation is different, and every state has different subtleties in the law. It is best to have a personal attorney and/or certified public accountant (CPA) work with you to develop a plan that suits your situation. This module gives an overview of commonly employed options that caregivers should know about. The particular language may vary from state to state.

Estate planning is a term used to describe how one handles financial affairs during life as well as at death. For persons of sizable means, it is well worth the investment to consult with a lawyer specialized in wills, trusts, and estates or elderlaw. In this way families can secure appropriate management of assets and minimize excess tax liability. There are options which allow an individual of substantial means to divest himself of assets so as to become Medicaid eligible. Such options should be carefully examined by those who want to minimize their tax liability while preserving their personal integrity. Even persons of average means are wise to investigate appropriate legal devices to preserve assets for paying for their own long term care. Living trusts and testamentary trusts are sometimes appropriate mechanisms for giving to charities and other causes.

For persons of modest means, it is especially important that money be handled carefully to keep the person as independent as possible for as long as possible. This may well involve several kinds of home care services, most of which are not covered by insurance. Being the "attorney in fact" as named in a durable power of attorney enables the caregiver to manage the money and avoid losses due to the care recipient's error. The "durable" aspect refers to specific language that ensures that the instrument will still be valid after incompetency is determined. This is one of the main reasons for having a power of attorney. In essence, the person can empower another TRUSTED person to make financial decisions for him or her when necessary. Having a specific person named can avoid misunderstandings among family members. TRUST is vital because the person is literally putting all his assets into the hands of another person. (You will be given a simple durable power of attorney. If you wish to use it, you can fill in the blanks yourself, but the signature must be made in the presence of a notary).

Wills are devices to direct what happens to assets at the time of death. In Virginia, if one dies intestate (without a will), all the deceased person's assets will automatically go to the spouse. Having a properly drawn will is usually best. If the estate is quite modest, however, and all assets are to be left to the spouse, it may not make sense to spend a limited amount of money to have a will drawn up.

To decide if you should investigate having a will and other devices drawn up, you need to figure out your net worth. Based on this figure, an attorney or CPA can suggest which devices, if any, would be to your advantage with respect to tax liability. To determine your net worth, you need to list the value of all your assets, and that of all your liabilities. The difference between the two will be your net worth.

Assets would include liquid assets (checking and savings accounts, certificates of deposit, etc.); personal residence and personal property (cars, antiques, silver, coins, etc.); pensions (IRAs, retirement plans, social security, etc.); life insurance policies; and investments (stocks, bonds, mutual funds, savings certificates, land, rental property, real estate, investment club holdings, etc.). Next, list your liabilities, that is, money owed on your house, cars, notes, credit cards, etc. The difference between your assets and liabilities will help you determine what kind of estate planning, if any, you need to arrange.

Title held jointly can sometimes be very easy to create, and no attorney is needed. For example, a joint bank account can be established by simply placing another person's name on the account. That person can then pay the bills with the money in that account when the care recipient is no longer able. Other forms of joint tenancy title have more complex ramifications. Legal advice should be sought when considering changing the form of title with real estate or other large assets. There are various kinds of joint tenancy, and an attorney is usually needed in order to determine the most beneficial kind.

Managing Medical Affairs

Of greater importance than adequately managing finances is carefully managing the medical treatment of the individual. Just as powers of attorney and wills and trusts are types of advance directives regarding assets and property, the "Living Will" and "Health Care Power of Attorney" are advance directives regarding our choices about what happens when we can no longer speak for ourselves. The "Living Will" provides for those who are terminally ill, and the more recently enacted "Health Care Power of Attorney" provides for other cases where death is not imminent.

Virginia was one of the first states to address the issue of determining one's fate in the case of terminal illness. The Virginia Natural Death Act, popularly known as the "Living Will," passed in 1983. Because it provided for substitute decision making in terminal cases only, a second type of advance directive (Surrogate Medical Decision Making Statute) was enacted in 1989. For the first time, the Health Care Power of Attorney was recognized by Virginia law. The statute also provides for more liberal decision making even when there is no advance directive.

There was some confusion and apparent conflict between the two statutes. The issue was revisited in 1992 when Virginia changed the Natural Death Act to allow support systems (including nutrition and hydration) to be terminated for a person in a persistent vegetative state. The "cleaning up" of the two previous statutes resulted in a new Virginia law called the **Health Care Decision Act, which became effective July 1, 1992.**

An Advance Directive is defined as "a witnessed written document, voluntarily executed by the declarant ..." Provision for a witnessed oral statement in terminal cases can be made before a doctor and two witnesses.

It is essential that the declarant be capable of making and communicating an informed decision. THEREFORE IT IS ESSENTIAL THAT PERSONS WITH AD EXECUTE THE DEVICE WHILE THEY ARE STILL COMPETENT TO DO SO. Once the devise has been signed before two witnesses who are not related by blood or a spouse, multiple copies can be made and distributed to all necessary parties--doctors, staff, hospitals, nursing home, hospice, etc. In addition, spiritual advisors such as pastors, rabbis, and priests should also have a copy. Any individuals named in the advance directive should have a copy. The copies will do. It is not necessary to show the original, which should be kept in a safe place.

In Virginia, the language of the two previous documents has been combined into one. You will be given an example which is a one page (two-sided) health care power of attorney consistent with the Code of Virginia (courtesy of the Virginia Hospital Association). In addition to the information addressed in this simple directive, you can develop a more elaborate document in which you specify your preferences regarding life-prolonging procedures such as the following: cardiopulmonary resuscitation (cpr), which attempts to restore breathing and heartbeat; intravenous (i.v.) therapy, which provides nutrition, hydration, and/or medications; feeding tubes; and machines which perform the work of the lungs (respirator) or kidneys (dialysis); etc. You can also indicate whether or not you want pain relief. It is also possible to name not only a primary but also second and third agents as surrogate decision makers. The more extensive directives, like the shorter one, need only for the declarant's signature to be witnessed by two witnesses who are not blood relatives or a spouse.

The Advanced Directive does not become effective until the declarant is incapable of making an informed decision. The person must be suffering from mental illness, mental retardation, or another mental or physical disorder that precludes communication or causes impaired judgment. The person must be unable to make "an informed decision about providing, withholding, or withdrawing a specific medical treatment or course of treatment because he is unable to understand the nature, extent or probable consequences of the proposed medical decision, or to make a rational evaluation of the risks and benefits of alternatives to that decision." These conditions must be certified not only by a physician, but also by a second physician or licensed clinical psychologist. Certification must be made not less than every 180 days so long as the treatment is being administered pursuant to the Advance Directive. The statute goes on to allow for "comfort care" and the administration of pain relieving medication.

It is the responsibility of the substitute decision maker(s) to determine the risk, benefits, and alternatives to treatment since the declarant can no longer do that. In addition, the substitute decision maker(s) should be aware of the person's religious beliefs and basic values and act in the person's best interests.

Like the general power of attorney, which allows for substitute decision making regarding the individual's financial affairs, the health care power of attorney should also contain language to be durable. That is, it will not terminate upon the incapacity of the principal, which is exactly when it is needed the most. Again, TRUST is vital because the individual is literally putting his life into another's hands.

As for the portability of the Advance Directive, the laws of the 50 states vary widely. A Virginia power may not be valid in other states. Virginia recognizes powers from other states, however, so long as they comply with Virginia law and the law of the state where initiated.

Without an Advance Directive, a physician may act upon the authorization of the following in order of priority: court appointed guardian or committee; spouse; adult child(ren); adult brother or sister; and any other relative in the descending order of the blood relationship. Obviously this can lead to conflict in the family about what to do. The physician acts on the majority of reasonably available members of that class.

The 1990 Omnibus Budget Reconciliation Act requires certain health care providers (hospitals, nursing homes, hospices, health maintenance organizations) and home health care providers who receive funds from either Medicare or Medicaid, beginning December 1, 1991, to take certain actions in support of the advance directives. For example, they must provide written information about advance directives, asking if there is an advance directive but not discriminating if there is not.

According to attorney Edward R. Parker (Parker, Pollard & Brown, P. C., Richmond, VA), "Advance Directives are potentially a great benefit to the American people in avoiding medical treatment that artificially extends the life of a disabled person in a way that can only bring pain and sorrow to the family, as well as require expenditure of huge sums for health care that is totally inappropriate . . . All of us who are giving care to our elderly and disabled need to promote the use of these legal instruments to help avoid what will often occur to those who have not executed an Advance Directive."

In summary, a durable Power of Attorney for Health Care is one of the most if not THE most important document that the care recipient can have. You can model your own document after one of the sample forms or your attorney can draw up a more personalized one. It does not have to be notarized, only witnessed.

ALL LEGAL DOCUMENTS SHOULD BE DRAWN OR REVIEWED BY AN ATTORNEY IN THE STATE OF RESIDENCE OF THE DECLARANT TO BE SURE OF THE VALIDITY OF THE DOCUMENT WITH RESPECT TO LANGUAGE AND RECENT CHANGES IN STATE LAW.

EXPERIENTIAL LEARNING:

1) Give out the Virginia Advance Medical Directive. Specifically read aloud the "Living Will" portion (in the box on the top part of the form). Point out that it refers ONLY to terminal conditions and ONLY to life-prolonging procedures. Note that the whole box can be crossed out if the person does not desire a "Living Will." The remaining portion of the document deals with appointing surrogate decision-maker(s), i.e., the primary and secondary agents. Allow a few minutes for the caregivers to read to themselves, making note that any part of the document they do not agree with can be marked out.

At their leisure, they can also carefully read and/or devise other more specific examples of advance directives. Encourage caregivers to discuss these legal options with their family members as soon as possible. Declarants may wish to address such issues as "do not resuscitate," organ donation, and specific treatments. Remind participants that anyone could meet with a tragic accident rendering them unable to make their own health care decisions. *Reinforce that all legal documents should be drawn up or reviewed by an attorney in the state of residence.*

2) Give out the sample "General Power of Attorney." Its validity requires signing in front of a notary, which is usually an inexpensive or free service.

3) At the end of this module is a handout from the National Institute on Aging. Distribute copies of the handout, and review the kinds of records that should be kept and resources available to caregivers.

REFERENCES:

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Alzheimer's Disease Center, University of Southern California. (1991). *Improving caregiving skills: The stress reduction method*. Silver Spring, MD: Alzheimer's Disease Education and Referral Center.

Parker, E. T. (1992). *Health care decision-making*. Paper presented at the Joint Conference of the Virginia Association on Aging and the Virginia Coalition for the Aging, Richmond, VA.

Virginia Hospital Association. (1992). *Your right to decide*. Richmond, VA.

VIRGINIA ADVANCE MEDICAL DIRECTIVE

This form, with slight variations, is the form approved by the Virginia General Assembly in the Health Care Decisions Act. The form contains both a "Living Will" portion and a "Durable Power of Attorney for Health Care" portion. You may complete either or both of these two portions of the form. Virginia law does not require the use of this particular form in order to make a valid advance directive. If you have legal questions about this form, or would like to develop a different form to meet your particular needs, you should talk with an attorney. You must sign your advance medical directive in the presence of two witnesses who are not blood relatives or your spouse. It is your responsibility under Virginia law to provide a copy of your advance directive to your attending physician. You also should provide copies of the directive to close relatives and/or friends.

ADVANCE MEDICAL DIRECTIVE made this ____________ day of ____________________, 19_____.
Month Year

I, ____, willfully and voluntarily make known my desire and do hereby declare:

(Cross through this box if you do not want to make a living will in this form.)

"Living Will" Portion of Advance Medical Directive

If at any time my attending physician should determine that I have a terminal condition where the application of life-prolonging procedures would serve only to artificially prolong the dying process. I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort care or to alleviate pain. (OPTION: I specifically direct that the following procedures or treatments be provided to me: ____

____)

In the absence of my ability to give directions regarding the use of such life-prolonging procedures, it is my intention that this declaration shall be honored by my family and physician as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences of such refusal.

(Cross through this box if you do not want to appoint an agent to make health care decisions for you.)

"Durable Power of Attorney for Health Care" Portion of Advance Medical Directive

I hereby appoint the following as my primary agent to make health care decisions on my behalf as authorized in this document:

____

____

If the above named primary agent is not reasonably available or is unable or unwilling to act as my agent, I then appoint the following as successor agent to serve in that capacity:

____

____

I hereby grant to my agent, named above, full power and authority to make health care decisions on my behalf as described below whenever I have been determined to be incapable of making an informed decision about providing, withholding or withdrawing medical treatment. The phrase "incapable of making an informed deci-

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sion" means unable to understand the nature, extent and probable consequences of a proposed medical decision or unable to make a rational evaluation of the risks and benefits of a proposed medical decision as compared with the risks and benefits of alternatives to that decision, or unable to communicate such understanding in any way. My agent's authority hereunder is effective as long as I am incapable of making an informed decision.

The determination that I am incapable of making an informed decision shall be made by my attending physician and a second physician or licensed clinical psychologist after a personal examination of me and shall be certified in writing. Such certification shall be required before treatment is withheld or withdrawn, and before, or as soon as reasonably practicable after, treatment is provided, and every 180 days thereafter while the treatment continues.

In exercising the power to make health care decisions on my behalf, my agent shall follow my desires and preferences stated in this document or as otherwise known to my agent. My agent shall be guided by my medical diagnosis and prognosis and any information provided by my physicians as to the intrusiveness, pain, risks, and side effects associated with treatment or nontreatment. My agent shall not authorize a course of treatment which he knows, or upon reasonable inquiry ought to know, is contrary to my religious beliefs or my basic values, whether expressed orally or in writing. If my agent cannot determine what treatment choice I would have made on my own behalf, then my agent shall make a choice for me based upon what he believes to be in my best interests.

Further, my agent shall not be liable for the costs of treatment pursuant to his/her authorization, based solely on that authorization.

OPTION: Powers of my agent. (Cross through any language you do not want and add any language you do want.)

The powers of my agent shall include the following:

A. To consent to or refuse or withdraw consent to any type of medical care, treatment, surgical procedure, diagnostic procedure, medication and the use of mechanical or other procedures that affect bodily function, including but not limited to artificial respiration, artificially administered nutrition and hydration, and cardiopulmonary resuscitation. This authorization specifically includes the power to consent to the administration of dosages of pain-relieving medication in excess of standard dosages in an amount sufficient to relieve pain, even if such medication carries the risk of addiction or inadvertently hastens my death;

B. To request, receive, and review any information, verbal or written, regarding my physical or mental health, including but not limited to medical and hospital records, and to consent to the disclosure of this information;

C. To employ and discharge my health care providers;

D. To authorize my admission to or discharge (including transfer to another facility) from any hospital, hospice, nursing home, adult home or other medical care facility; and

E. To take any lawful actions that may be necessary to carry out these decisions, including the granting of releases of liability to medical providers.

This advance directive shall not terminate in the event of my disability. By signing below, I indicate that I am emotionally and mentally competent to make this advance directive and that I understand the purpose and effect of this document.

Date ______________________ Signature of declarant ______________________

The declarant signed the foregoing advance directive in my presence. I am not the spouse or a blood relative of the declarant.

Witness ______________________

Witness ______________________

This form is provided by the Virginia Hospital Association as a service to its members (August 1992)

ADVANCE DIRECTIVE

(This legal document has been designated an "Advance Directive" by the Virginia Health Care Decisions Act Pursuant to Code of Virginia, Sections 54.1-2981 through 2992. This Advance Directive could also be described as a Health Care Power of Attorney, a Medical Power of Attorney, a Power of Attorney for Health Care or a Medical Proxy. The terms of the Advance Directive include language usually found in a "Living Will".

I, JOHN DOE, willfully and voluntarily make known my desire and do hereby declare:

If at any time my attending physician should determine:

a. *I have a condition that is incurable or irreversible and, without the administration of life-sustaining treatment, expected to result in death within a relatively short time, or*

b. *I am in a coma or persistent vegetative state which is reasonably concluded to be irreversible,*

where the application of life-prolonging procedures would serve only to artificially prolong the dying process, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort care or to alleviate pain.

With respect to Nutrition and Hydration provided by means of a nasogastric tube or tube into the stomach, intestines, or veins, I wish to make clear that I intend to include these procedures among the "life-prolonging procedures" that may be withheld or withdrawn under the conditions given above.

In the absence of my ability to give directions regarding the use of such life-prolonging procedures, it is my intention that this declaration shall be honored by my family and physician as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences of such refusal.

I hereby appoint MARY L. DOE of:

Address: 123 North Street, Richmond, VA 23222

Telephone: (Home) (804) 346-9999

as my Agent to make health care decisions on my behalf as authorized in this document. If Mary L. Doe is not reasonably available or is unable or unwilling to act as my Agent, then I appoint **WILLIAM S. DOE** to serve in that capacity.

Address and telephone number of William S. Doe: 345 South Main Street, Lynchburg, VA 24555; (Home) (703) 435-0119

I hereby grant to my Agent, named above, full power and authority to make health care decisions on my behalf as described below whenever I have been determined to be incapable of making an informed decision about providing, withholding or withdrawing medical treatment. The phrase "incapable of making an informed decision" means unable to understand the nature, extent and probable consequences of a proposed medical decision or unable to make a rational evaluation of the risks and benefits of a proposed medical decision as compared with the risks and benefits of alternatives to that decision, or unable to communicate such understanding in any way. My Agent's authority hereunder is effective as long as I am incapable of making an informed decision.

The determination that I am incapable of making an informed decision shall be made by my attending physician and a second physician or licensed clinical psychologist after a personal examination of me and shall be certified in writing. Such certification shall be required before treatment is withheld or withdrawn, and before, or as soon as reasonable practicable after, treatment is provided, and every 180 days thereafter while the treatment continues.

In exercising the power to make health care decisions on my behalf, my Agent shall follow my desires and preferences as stated in this document or as otherwise known to my Agent. My Agent shall be guided by my medical diagnosis and prognosis and any information provided by my physicians as to the intrusiveness, pain, risks, and side effects associated with treatment or nontreatment. My Agent shall not authorize a course of treatment which he knows, or upon reasonable inquiry ought to know, is contrary to my religious beliefs or my basic values, whether expressed orally or in writing. If my Agent cannot determine what treatment choice I would have made on my own behalf, then my Agent shall make a choice for me based upon what he believes to be in my best interests.

The powers of my Agent shall include the following:

A. To consent to or refuse or withdraw consent to any type of medical care, treatment, surgical procedure, diagnostic procedure, medication and the use of mechanical or other procedures that affect any bodily function, including, but not limited to, artificial respiration, artificially administered nutrition and hydration, and cardiopulmonary resuscitation. This

authorization specifically includes the power to consent to the administration of excess dosages of pain relieving medication, even if such medication carries the risk of addiction or inadvertently hastens my death:

B. To request, receive, and review any information, verbal or written, regarding my physical or mental health, including but not limited to, medical and hospital records, and to consent to the disclosure of this information;

C. To employ and discharge my health care providers;

D. To authorize my admission to or discharge (including transfer to another facility) from any hospital, hospice, nursing home, adult home or other medical care facility; and

E. To make anatomical gifts of part or all of my body for medical purposes, authorize an autopsy, and direct the disposition of my remains to the extent permitted by law;

F. To authorize the entry of a Do Not Resuscitate (DNR) Order including an Emergency Medical Services Do Not Resuscitate Order;

G. To take any lawful actions that may be necessary to carry out these decisions, including the granting of releases of liability to medical providers.

Further, my Agent shall not be liable for the costs of treatment pursuant to his authorization, based solely on that authorization.

Words of any gender used in this instrument shall be held to include any other gender and words in the singular shall be held to include the plural when the sense requires.

This advance directive shall not terminate in the event of my disability.

By signing below, I indicate that I am emotionally and mentally competent to make this advance directive and that I understand the purpose and effect of this document.

Signature: ____________________________ Date: September 14, 1992
Name: JOHN DOE

The declarant signed the foregoing advance directive in my presence. I am not the spouse or a blood relative of the declarant.

____________________________ Richmond, Virginia

____________________________ Richmond, Virginia

NOTARIZATION

STATE OF VIRGINIA AT LARGE

COUNTY OF HENRICO, to-wit:

On this 14th day of September, 1992, the said John Doe, known to me (or satisfactorily proven) to be the person named in the foregoing instrument, personally appeared before me, A Notary Public, within and for the State and County aforesaid, and acknowledged that he or she freely and voluntarily executed the same for the purposes stated therein.

My commission expires: ________________

____
NOTARY PUBLIC

(Italics indicate material added to the statutory Advance Directive by Parker, Pollard & Brown, P.C.)

Used with permission of Parker, Pollard & Brown, P.C., 5511 Staples Mill Road
Richmond, Virginia 23228 804/262-4042

GENERAL POWER OF ATTORNEY

I, ________________________, of ________________________, Virginia, do hereby appoint ________________________, of ____________________________, Virginia, my attorney in fact, for me and in my name, place and stead, (1) to ask, demand, sue for, recover, and receive, of and from all corporations, associations, entities and persons whatsoever (i) each and every piece or parcel of realty and article of personalty which I own or which I am entitled to possess, and (ii) each and every sum of money or right due and owing or that may become due and owing to me on any and every account, contract, or tort, whether due or to become due, or, at my attorney's discretion, to arbitrate or compromise for the same, and give discharges; (2) to sign any bond, deed, obligation, contract, court order, pleading or process, tax return (including the consent required under IRC 2513), or any other paper; (3) to draw upon any banks or other financial institutions, or any corporations, associations, entities, or individuals for any sum or sums of money that may be to my credit, or which I may be entitled to receive; (4) to borrow money in my name on such terms as my attorney may deem appropriate and to execute and deliver any documents necessary to give any lender a security interest in any or all of my real and/or personal property in connection with any loan; (5) to sell or lease any part or parts of my real or personal estate, wheresoever situated, upon such terms as my attorney may deem appropriate, and to make all necessary deeds and conveyances thereof, with all necessary covenants, warranties, and assurances, and to sign, seal, acknowledge, and deliver the same; (6) to enter any safe deposit box that I may be the lessee of or otherwise entitled to enter in any bank or other institution; (7) to borrow against or obtain the cash surrender value of any of my life insurance policies, and to transfer the ownership of any such policies to the beneficiary(s) names therein; (8) to create, and to add to, inter vivos trusts for my benefit; (9) to make gifts to beneficiaries named in my will by way of total or partial satisfaction of any bequests or devises made to such beneficiaries in my will as written at the time of such gifts; and (10) to do all such other acts, matters, and things in relation to all or any part of or interest in my property, estate, affairs, or business, of any kind or description, in the state of Virginia, or elsewhere, as I myself might or could do if acting personally.

This power shall become effective as to third parties when recorded in the Clerk's Office of the Circuit Court for the jurisdiction where I reside at the time of the execution of this power, and it may be annulled at any time after the execution hereof by an instrument of revocation being recorded in the same place. This power of attorney shall not terminate on disability of the principal.

WITNESS the following signature and seal, this ___ day of __________, 19__.

________________________ (SEAL)
Principal

STATE OF VIRGINIA:

______ of ___________

The foregoing instrument was executed and acknowledged before me by the above-named Principal this ___ day of ________, 19__.

National Institute on Aging

Age Page

Getting Your Affairs in Order

One thing each of us, young and old, can do to plan for the future is to get our financial and personal records in order. These records can be useful for budgeting income, for making investments, or for retirement and estate planning.

Older people sometimes need help from relatives and friends with managing their legal or financial affairs—either temporarily or by having these responsibilities gradually assumed. Because the person who provides care often has little knowledge of vital information and records, the task is much simpler if papers are already in order.

Each situation is different, but the following suggestions may help you to begin organizing your financial and personal records.

Personal Records

A personal records file should include the following information:

- Full legal name
- Social Security number
- Legal residence
- Date and place of birth
- Names and addresses of spouse and children (or location of death certificate if any are deceased)
- Location of will or trust
- Location of birth certificate and certificates of marriage, divorce, and citizenship
- List of employers and dates of employment
- Education and military records
- Religious affiliation, name of church or synagogue, and names of clergy
- Memberships in organizations and awards received
- Names and addresses of close friends, relatives, doctors, and lawyers or financial advisors
- Request, preferences, or prearrangements for burial.

A family member or friend should know the location of this personal records file and the location of all important papers and documents, although it is not necessary to reveal the contents of wills or trusts.

Financial Records

A financial records file is a place to list information about insurance policies, bank accounts, deeds, investments, and other valuables. Here is a suggested outline:

- Sources of income and assets (pension funds, interest income, etc.)
- Social Security and Medicare information
- Investment income (stocks, bonds, property)
- Insurance information (life, health, and property), with policy numbers
- Bank accounts (checking, savings, and credit union)
- Location of safe deposit boxes
- Copy of most recent income tax return
- Liabilities—what is owed to whom and when payments are due
- Mortgages and debts—how and when paid

- Credit card and charge account names and numbers
- Property taxes
- Location of all personal items such as jewelry or family treasures.

Having this information available can help you plan for any changes that might come up in the years ahead— such as retirement, a move, or a death in the family—by providing you with the needed details to make the best decisions.

An important consideration in financial planning is the cost of medical services and long-term care, although there is often no easy or simple way to determine how to meet these future needs. It is important to learn what is and is not covered by Medicare, the program under the Social Security Administration that provides medical care for older people. For example, Medicare does not cover most nursing home or home care. Medicaid is a program for people with limited income and pays for some community services. New laws may change Medicare and Medicaid coverage; but meanwhile, you may wish to explore the long-term care insurance options that are beginning to develop. State laws vary, so it is important to check with your area office on aging, a lawyer, or financial planner for information related to estates, inheritance, taxes, insurance, Medicaid, or Medicare.

Caring for an older person or preparing for your own old age can be more successfully managed by making decisions and arrangements before a crisis develops. Three legal documents (power of attorney, durable power of attorney, and living will) can be helpful in assuming responsibility for another person's affairs. A standard power of attorney or durable power of attorney can be set up to give one person power to handle personal or financial matters for another. Because the standard power of attorney loses its effectiveness if the principal becomes legally incompetent, a durable power of attorney is better. A durable power of attorney continues even if a person becomes incapacitated. A living will provides written instructions concerning health care in the event of terminal illness. Living wills are recognized in most, but not all, states. The living will makes it easier for a person to know how to make difficult health care decisions on a relative's behalf and can help avoid family conflict.

Resources

Consult a lawyer before setting up a power of attorney, durable power of attorney, joint account, trust, or guardianship. Be sure to ask for the cost of a legal consultation before visiting a lawyer. For help in locating a lawyer, most libraries have legal directories or write to the American Bar Association's Lawyer Referral and Information Service at 750 North Lake Shore Drive, Chicago, IL 60611.

Free legal and financial services are often available to help older people and their families. For assistance, contact one of the following organizations and they will refer you to a local or state agency on aging: National Association of Area Agencies on Aging, 600 Maryland Avenue, SW., Suite 208, Washington, DC 20024; or the National Association of State Units on Aging, 2033 K Street, NW., Suite 304, Washington, DC 20006.

The National Institute on Aging provides information on health and aging. Write to the NIA Information Center, P.O. Box 8057, Gaithersburg, MD 20898-8057.

1991

Module 6: The Grieving Process

GOAL: To understand grief as a normal and healthy response to loss, and to increase knowledge and understanding of the stages of grieving and how they apply to the care recipient and caregiver.

RATIONALE: Care providers who understand the grief process are able to face the grief they and their care recipients experience, and understand their various reactions as normal responses to grief.

EDUCATIONAL OBJECTIVES: At the end of this module, caregivers should be able to:

1) List the stages a person may go through in normal grieving, including individual variability.
2) Describe and discuss the particular grief experiences of the caregiver of a person with dementia.
3) Discuss the concepts of mental death versus physical death, and the impact of "mental death" on the caregiver.
4) Describe "anticipatory" grief.
5) List and discuss at least three difficult facts about Alzheimer's which enable the caregiver to cope with anticipatory grief.
6) List and discuss at least three factors which can affect the acceptance of loss.

MINI-LECTURE:

The Nature of Grief

In Alzheimer's disease, the grief process begins long before the care recipient dies. Not only does the family grieve over the loss of the person they once knew, but the person with AD may have enough awareness of the progression of the disease to grieve for their own impending loss.

Grieving is a normal, healthy process experienced in reaction to loss. When caregivers understand the various stages of grief and the special aspects of grieving for a loved one with dementia, they can deal with their own grief and the grief of the care recipient with better understanding.

For the caregivers of persons with AD, grief often begins with, or soon after, the diagnosis. As a consequence, families experience loss while their loved one is still alive. They have often completed much of the grief process before death arrives. The individual with AD, too, may experience grief in the early stages of the disease, when they understand what is occurring.

Death has always been a point for grieving. The dementia of Alzheimer's, however, causes loss of a person in a profound way, and perhaps a more agonizing way. Being able to grieve the loss of the person the caregiver once knew can normalize the feelings the caregiver has.

Unfortunately, our stoic society is a long way from affirming the normal process of grieving. Someone who "goes to pieces" is seen as unpredictable and frightening. As one author notes, ". . . we want (the out-of-control) to 'get it together', so we sedate them, convert them, or divert them. We try our best to get them to stop being so threatening." Grief is terrible. It is terrifying to lose something of real value, but it is through grieving that loss is accepted and recovery is accomplished.

Dr. Kubler-Ross (1969) writes about the psychological stages she observed the terminally ill go through. These same stages are applicable to the families and caregivers of the terminally ill. In reviewing the stages of grieving, it is important to keep in mind that not everyone goes through each stage. Individuals also differ with respect to the order and rate at which stages are experienced. Experiencing each stage is normal, as is skipping a stage or passing quickly through it.

The stages of dying (and grieving) as seen by Dr. Kubler-Ross are as follows:

> 1. Denial and isolation - "No, not me; the doctor made a mistake!" Other medical opinions may be sought - anything to disprove the dreaded diagnosis. At times, terminally ill persons may withdraw, isolating themselves from others as they grapple with the dire news. The family may attribute the dementia to "simple forgetfulness" until denial is overcome by the reality of increasing dementia.
>
> Denial can be a positive adaptive coping mechanism for caregivers and persons with AD. The effectiveness of this coping mechanism will naturally decrease as impairment increases. On the other hand, if the diagnosis is accepted too easily, it may be because of stress avoidance at an emotional level. If this occurs, individuals may not be motivated to make

the behavior changes necessary to deal with the new reality. In this case, the capacity to absorb new information may be very limited.

2. Anger and resentment - Denial often gives way to anger, which can be directed at anybody - family members, nurses, doctors. The ill person or the caregiver may lash out at what is seen as the unfairness of the illness, and resent those who are seen as healthy and whole. Nothing is right and it is the fault of everyone else. Questions such as "Why me?" or "Why my husband?" characterize this stage.

The caregiver tries to retrieve the "good old days," and finds it an impossible task. Denial and frustration lead to anger, envy and resentment of relatives and acquaintances. These negative feelings can even be directed toward people who care most about the caregiver and the care recipient.

When anger is seen as a reaction to the magnitude of the loss, it becomes understandable. It can be difficult to cope with, however, because of the reaction of family members and other caregivers to the anger. If the loss is acknowledged and the person can express the anger without being abandoned, the anger will gradually subside.

3. Bargaining - As anger subsides a person may go through a brief period of bargaining: "I'll never argue with my wife again if only this won't happen to her." The bargaining is often a "secret pact" with a higher being: "Dear G-d, if this will stop, I'll serve you for the rest of my life."

This is a time when a person may also feel guilty about things done or said, or left undone or unsaid in the past. There may be a feeling of desperation to have a chance to make amends.

4. Depression - Depression occurs when the illness can no longer be denied. There is a sense of great loss as a caregiver or care recipient faces the reality of the disease. Dr. Kubler-Ross sees this as preparing for the separation from this world, when it is important and appropriate to feel and express sadness. Anguish and anxiety must be worked through, often with the help of clergy, social workers or others.

For the caregiver of a person with dementia, there is separation from the person once known. There are unfulfilled hopes and desires, increasing physical dependency, loss of control over one's life as demands increase, and deprivation of formerly enjoyable activities which have become embarrassing or impossible.

There is also uncertainty about the rate of progression of the disease. The caregiver's view of the future can be bleak as the relationship with their loved one changes and new roles are assumed. In their new roles, the caregiver and other family members must become the authority figures and make all the decisions. Depression is a normal stage, which, when eventually "worked through," can lead finally to acceptance.

5. Acceptance - For the non-demented, terminally-ill person, this is the time when the struggling is over. Peace and acceptance are accompanied by a withdrawing from this life as the circle of interest diminishes. During this stage the family needs more support and reassurance than the care recipient. Acceptance does not mean happiness. It does mean one is coping with the inevitable.

For caregivers of persons with dementia, this is a time when they realize that there is nothing they can do to change their loved ones' conditions. Caregivers come to understand that they do not need to feel guilty or inadequate when their help fails to result in improvement. There is a degree of emotional and intellectual separation from the care recipient. Caregivers no longer expect their loved ones to be the people they once were, or the people they want them to be. During this phase, caregivers come to understand that it is not life that is hopeless; it is the illness that is hopeless, irreversible and deteriorative. Author David Carroll (1989) writes:

> Now is the time to grieve, to cry, and to begin severing the many emotional strings that, Gulliver-like, keep you tied to your former companion. As something in the patient dies each day, something in you will die too, until the death process is complete in both of you. What is important at this period is to realize that you are in a pattern of mourning and that this pattern has a beginning, a middle, and an end. No matter how endless it feels right now, it will not be forever. That's important. Acceptance will help. In fact, acceptance is the key.

Coping with the Loss

Powell and Courtice (1983) write: "The purpose of grief and mourning is to accept the reality of the loss and begin to find new ways of filling up the emptiness caused by the loss." "Grief work" is the term used to describe the grieving process, for it is indeed work, and difficult work at that.

Some individuals with AD understand the diagnosis of their illness and are able to grieve for their own loss, and for the sorrow it brings their family. There are films showing people in the early stages of Alzheimer's who talk about the effect of the disease on their lives (see Audio Visual Reinforcement section of this Lesson Plan). Recently, Diana Friel McGowan, who is in the early stages of Alzheimer's disease, has written a widely publicized book chronicling her own losses (1993). Beyond a point, however, the person with AD loses the ability to grieve, and grieving becomes the burden of the caregiver alone.

Grieving is made more difficult when the mentally impaired person is unable to engage in the process of life review or otherwise share in the grief process. This places an additional burden on the caregiver who witnesses the slow death without the sense of completion. Of course, it is true that some people find the disease easier to accept than others, and that at times it is easier to accept what is happening than it is at other times.

Alzheimer's causes a loss of a person in a profound, and perhaps more agonizing, way than in death. Death is open, it is acknowledged, it is final. It has rituals to mark its finality. There is no ritual for the death of the mind. This, along with society's discomfort with visible grieving, can make it doubly difficult for the caregiver. Being able to grieve the loss of the person the caregiver once knew, however, can normalize the caregiver's feelings.

For the person with AD, death comes at the end of what is sometimes a long dying process. For the caregiver, caring for the mentally impaired is bereavement with no end in sight. It is grieving for what is never going to happen, as well as for what has already occurred. There will be no more movies, dinners or trips together. Loss after loss is faced and compiled day after day.

As difficult as it is to accept, Alzheimer's disease causes changes in personality so profound that eventually the person who resides in the body of the care recipient is not the person who was once known. These changes are, in themselves, the source of prolonged grieving. The original person has been lost, but not exactly. His or her mind is dying, but the body lives on. The caregiver now finds it necessary to separate emotionally and intellectually, while the person with AD is still physically existent.

Caregivers may find themselves thinking about their loved ones dying, or even wishing at times for death to occur. Despite the guilt that may accompany these wishes, they are normal and experienced by many who care for the terminally ill.

Grieving is present on two levels. It exists for the losses which have occurred, and also for the losses anticipated. **Anticipatory grief** is mourning the loss which will occur. It is mourning not just death at some indeterminate time, but each loss one faces as dementia worsens.

Anticipatory grief begins the day the diagnosis is delivered. The following are some difficult facts which can help a caregiver work through the grief.

(1) Dementia is a progressively degenerative disease, and its effects are irreversible.

(2) Spontaneous "cures" and "reversals" are extremely rare among persons with AD.

(3) People with AD will lose ". . . their most vaunted cognitive faculties, their sympathy, their insight, their humanity; slowly, invariably, these traits will vanish, one after the other, like leaves falling from a great tree (Carroll, 1989)."

(4) The disease stems from disintegration of the brain tissues, which means the person will die. Carroll writes that this is an "anguishing bullet to bite." However, it can be liberating to view the disease as it really is, without denial. Then steps can be taken to use time and energy wisely in locating resources, arranging for long-term care, and in allowing time for sorrow and to say goodbye.

The family can be a strong support system during the illness if members understand the disease process, and if it is recognized that each member must face the disease in their own way. Each person must work through the stages of grieving to find acceptance of the disease. This includes receiving encouragement and support and possibly professional help. If there are long-standing conflicts and repressed feelings, a professional counselor may be needed to resolve these.

The caregiver and family members need to share the pain and grief with other caregivers in support groups, with friends and with professionals. They may be surprised at how many people have undergone a similar experience. Their advice and recollections can help.

There are several factors which can affect the success of grief work and the acceptance of loss:

(1) Age at the time of the diagnosis. Caregiving is different if the care recipient was the breadwinner, and the healthy spouse must continue working while also providing care.

(2) General health of the person with AD. The care recipient and the caregiver may feel that the former has been "cheated by life," especially when an otherwise healthy individual begins the inescapable decline of Alzheimer's.

(3) Length of illness. The emotional, physical and financial strain intensifies the feelings of abandonment and loss. There is no way to tell how many months or years a person will be a caregiver.

(4) Family expectations. Alzheimer's may not be what they expected at all. As they learn more about the disease, they may be disappointed in the response of health professionals who can offer no real hope for recovery.

(5) Family's emotional closeness. There are tremendous barriers to communication with the care recipient because of the loss of social and intellectual capabilities. Some families are unable to counteract the sense of separation and isolation from the person with Alzheimer's.

(6) Pre-existing family roles. Family members must assume new roles as the person with AD loses the ability to function as they once did. For example, a man may have handled all the household finances. Now his wife must assume a role which is unfamiliar, "rightfully belongs" to her husband, and is an addition to the burden of caregiving.

The caregiver finds that expectations about what their loved one is still able to do must be changed. The care recipient should not be expected to fill all of the roles that they so easily filled previously. With acceptance can come the realization that life is not hopeless. It is the illness that is hopeless, irreversible and deteriorative.

David Carroll (1989) writes this advice:

> Take it a day at a time. Mark each loss as it occurs, and don't try to sweep it under the rug: It's here to stay. Recognize that even though the body in the wheelchair appears healthy enough, the mind inside it is declining, and with it the personality. This is reality. This is how it is.

Carroll (1989) also writes about fighting and denying the disease. He notes that when the frantic avoidance ends and acceptance begins, a "kind of inner quiet dawns."

When death does arrive, the caregiver may be astonished at the amount of grief which accompanies the relief and the feeling of emptiness. Alternatively, the caregiver may find that the grieving process has already been completed. There is no "right" or "wrong" way to feel when death comes. So many hours which have been filled with caregiving are now empty. The purpose of grieving and mourning during the illness and at death is to accept the reality of the loss and begin to find new ways of filling up the emptiness caused by the loss.

AUDIO-VISUAL REINFORCEMENT:

"Dying, Death and Bereavement" (in the series "Growing Old in a New Age") produced and distributed by The Annenberg/CPB Collection, P.O. Box 2345, S. Burlington, VT 05407-2345, (1-800-LEARNER).

"Early Onset Memory Loss: A Conversation with Lettie Tennis." Distributed through the Alzheimer's Association.

"Course and Outcome" (Part 3 in the series "Understanding & Coping with Dementia") produced by Sandoz Pharmaceutical Corp. Distributed through the Alzheimer's Association.

EXPERIENTIAL LEARNING:

The trainer should lead a group discussion concerning one or both of the following topics:

1) The five stages of grief which a terminally ill person and his family may experience. Have members of the discussion group give examples of ways a person expresses himself during the different stages (e.g., constant complaining about services as an example of anger).

2) The particular grief faced by those who care for individuals with dementia, and by some persons with AD. If group members feel comfortable doing so they should be encouraged to share losses that they have experienced. They should also offer suggestions to each other about how to cope with loss and grief.

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Coughlan, P. B. (1993). Facing Alzheimer's: Family caregivers speak. New York: Ballantine Books.

Konek, C. W. (1991). Daddyboy. St. Paul, Minn: Graywolf Press.

Kubler-Ross, E. (1969). On death and dying. New York: MacMillan.

McGowin, D. F. (1993). Living in the labyrinth. San Francisco, CA: Elder Books.

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Powell, L. S., & Courtice, K. (1983). Alzheimer's disease: A guide for the family. Reading, MA: Addison-Wesley.

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Melissa Ferrell is gratefully acknowledged as the major contributor to this module.

The Middle Stages

Module 7: Managing the Daily Routine
Module 8: Safety and Environmental Adaptations
Module 9: Formal Supports and Resources
Module 10: Managing Episodes of Aggressive or Hostile Behavior
Module 11: Managing Resistive Behavior Associated with ADLs
Module 12: Managing Wandering
Module 13: Communicating with The Person Who Has Alzheimer's Disease
Module 14: The Caregiver's Spiritual Resources
Module 15: Compassionate Caregiving
Module 16: Drug Treatment: Side Effects and Misuse
Module 17: Alcoholism and Alcohol Abuse: What African American Caregivers Need to Know About Risks

Module 7: Managing the Daily Routine

GOAL: To increase the caregivers awareness of barriers to effective care, strategies to enhance and encourage self-care, and management techniques for dealing with daily routine activities.

RATIONALE: When effective, consistent approaches to activities of daily living are maintained, persons with Alzheimer's Disease and other dementias can remain independent and functional for a longer period of time.

EDUCATIONAL OBJECTIVES: At the end of this module, caregivers should be able to:

1) Identify ways to simplify the bathing task.
2) Outline the process for giving a bedbath or bed shampoo.
3) Describe how dressing can be accomplished most effectively.
4) List some of the difficulties that challenge the need for good nutrition.
5) Discuss some ways to encourage exercise and maintain mobility.
6) Describe the correct way to use a cane or walker.
7) Outline the process for transferring a person from bed to chair.
8) Explain how to turn a person in the bed to prevent skin breakdown.

MINI-LECTURE:

In almost any home setting one family member (usually a female) spends more time with the person with Alzheimer's Disease than anyone else. This caregiver knows the functional abilities of the person better than others. The caregiver, however, may not always understand the importance of having the care recipient remain active and involved in their own care for as long as possible.

Activities of daily living are more than just necessary everyday tasks of the person with Alzheimer's; they provide an opportunity for socialization, mental stimulation, fun, and physical activity. This can also be a time for caregivers to assess any changes in the person's functional or emotional status.

Traditionally activities of daily living refer to bathing, dressing, toileting, feeding, personal grooming, communication and exercise. This module will address some of the daily living tasks (i.e., bathing and shampooing, grooming and dressing, eating and nutrition, and exercise and mobility). Caregivers will be shown how to best help the person with AD complete them.

Bathing

Bathing can be a rewarding activity for both caregiver and the person receiving the care. When first approaching the bathing task, caregivers should ask themselves the following questions:

1) Has the person been accustomed to a bath or a shower?
2) Did he or she bathe in the morning or at night?
3) Did he or she bathe daily, twice weekly, or less often?
4) Has clothing been changed daily, twice daily or weekly?
5) Has the person been shy or very private in his personal care?

A person with Alzheimer's Disease may not remember when he or she last took a bath. They may think it was just a few hours before the caregiver mentioned it or last evening before going to bed. Time very often becomes meaningless to the person.

Bathing is a very private task, and we all have our own set routine that is unique to us. Caregivers must be aware that the same holds true for the person they are caring for. Any change in normal routine can be devastating; it can cause increased confusion and possible resistive behaviors (see Caregiver Lesson Plan on Managing Resistive Behavior Associated with ADLs). Caregivers should learn the habits and routines of the person in their care to make caregiving more meaningful and avoid conflict.

The person with Alzheimer's may also be embarrassed, uncomfortable or even ashamed that someone else has to help with bathing. For instance if a male is being cared for by a woman who is not his wife, he may feel ashamed if the caregiver sees the most private areas of his body. Providing privacy, maintaining the person's dignity, and encouraging independence will help to make the bathing experience more enjoyable.

When giving a bath, make it as simple as possible.

1) Try to follow old routines as much as possible.
2) Lay out clothes and towels; then start the water.
3) Check the water temperature before allowing the person in the water.
4) Avoid discussion about whether a bath is needed or not.
5) Be calm and give directions one step at a time.

6) Allow the person as much independence in activity as possible. Bathing is a form of exercise so it is important for the person to bathe him/herself as often as possible.
7) Have them wash their own genitalia but observe closely for proper cleansing.
8) Observe for proper drying especially genitalia and under breasts.
9) Apply body lotion on dry skin. Use unscented for men.

As the person with AD passes into more physically debilitating stages, it may be necessary to perform a bed bath.

1) A bedbath requires that all supplies needed must be brought to the person's bedside before beginning.
2) A bathblanket is optional, but can be made out of sewing several towels together.
3) Keep the person covered so that they do not get cold. Wash his face first without soap. Be careful not to have washcloth edges dangling.
4) Wash the ears next. Place the towel under the person's head and dry carefully.
5) Place the towel under one arm; wash, then dry. Do the same to the other arm. Check the person's nail condition when washing her hands.
6) Uncover the chest and wash, rinse and dry. Pay particular attention to the folds under a female's breast. Powder LIGHTLY. Too much powder can form small hard granules under skin folds and cause irritation and broken skin.
7) Turn the person onto one side, tuck the towel under the buttocks and along her back. Wash, rinse and dry. Apply lotion to back and buttocks. Cover the person up as soon as possible.
8) Put the towel under the buttocks and wash, rinse and dry. When washing females, pay particular attention to wash from the front of the genital area to the back. This will avoid fecal bacteria from entering the vagina and causing infection.
9) Apply lotion as needed.

The bedbath should be a source of enjoyment, as well as a necessary procedure. If a tub bath, shower or bedbath is not feasible, a sponge bath may be in order. This is a very individual action and the caregiver has to use his or her own judgment about when this is warranted.

Safety Tips on Bathing (see also Caregiver Lesson Plan on Safety and Environmental Adaptations):

1) Since people with Alzheimer's lose the ability to gauge temperature, water temperature should always be checked by the caregiver before allowing the person to get in the water.
2) Bubble bath or bath oils should not be used since they can cause tubs to become slippery and contribute to accidents.
3) Have only have three inches of water in the bathtub.
4) Never leave the person alone in the bath.
5) Install a non-slip mat in the bottom of the tub to prevent slipping.
6) Install a tub seat and grab rails if the person takes a shower.
7) Place a non-slip bathmat outside the tub to prevent slipping.
8) Check the person's body for sores, reddened areas or rashes.
9) If the person becomes frightened or angry or uncooperative during the bath, stop the procedure as quickly as possible.
10) Do not force a procedure.

Bed Shampoo

Before giving a shampoo to someone in bed, it is important to have everything that will be needed to complete the task. There are dry shampoos sold that require only applying to the hair and then brushing out thoroughly. While those products have their place, the most common type of shampoo given is wet.

To give a bed shampoo the following steps should be followed:

1) Replace the pillowcase with a plastic cover and place plastic cover under shoulders (garbage bags can be used).
2) Loosen the person's gown around the neck, place a towel under his shoulders and bring around his neck and pin it.
3) Raise the person's head and place it in the shampoo trough (can be purchased at any medical supply center).
4) Give the person a washcloth to hold over her eyes.
5) Pour a small amount of warm water over the hair and apply a small amount of shampoo and work gently into the hair with fingertips.
6) Rinse thoroughly and repeat shampoo application if necessary.
7) Dry the person's face and ears, wrap her hair in a towel and remove the trough.
8) Dry the person's hair, put another dry towel around her neck and begin combing and drying with a hair dryer.

9) Care should be taken to use a hair dryer on a low setting to prevent burns.
10) All bed linen should be left dry and pillowcase put back on.

Grooming and Dressing

Grooming is an activity the person with Alzheimer's Disease has performed independently and in private since early childhood. Maintaining independence, privacy and self-esteem for as long as possible is clearly a priority.

Activities include shaving, oral care, brushing and combing hair, and dressing. Such activities require complex thinking. As Alzheimer's Disease progresses, those thinking processes decline dramatically.

1) Have women's hair cut in a short but attractive style that is easily managed.
2) Women should continue to go to the hairdresser for as long as possible if this was their routine.
3) Men's socks should all be the same color. Tube socks are good because they do not have a heel.
4) For women, hang slip, dress and sweater on the same hanger. For men, hang slacks, shirt and sweater or jacket together.
5) Use slacks or pants with elastic waistlines.
6) Avoid clothing with hooks, buttons, snaps and zippers when possible.
7) Wash hair at the kitchen sink unless there is a handheld shower sprayer available. This is easier than trying to wash the person's hair while the person is in the tub.
8) Use "no tears" shampoo when washing hair. If the person becomes restless and uncooperative this will not irritate the eyes.
9) Trim finger and toe nails as needed. If there is a problem with bunions, ingrown toenails or corns, the person should be seen by a foot specialist.
10) Perform oral care at least twice a day and talk the person through the procedure if they have forgotten the steps.

Dressing and grooming can be difficult for the person with Alzheimer's Disease to perform. Caregivers can make it easier for the person by following a few simple steps.

In the earlier stages of the disease, the person with AD needs only to be reminded about bathing, dressing, or grooming. As the disease progresses the caregiver will have to direct and show the person how to perform these activities. In the final stages, the caregiver will be doing most of the care necessary because of the deteriorating condition of the person.

1) While the person can still dress, encourage independence.
2) Break the task into steps; demonstrate each step, coax the person to perform, and give them ample time to complete the task.
3) Lay clothing out in the order to be put on.
4) Give only two choices of clothing (or less!) to wear.
5) Caregivers could consider replacing belts and buttons etc. with Velcro closures.
6) Do NOT take over the task because the person is slow.

Eating and Nutrition

A well-balanced diet is important for normal growth and functioning. Food provides the energy needed to perform the activities of daily living. Making sure that persons with Alzheimer's Disease eat a proper diet with the required nutrients can be a challenge to the caregivers.

Good sound nutritional habits are critical for persons with Alzheimer's Disease and their caregivers. Often the person forgets to eat or eats the same foods every day whatever the nutritional value. Consequently, nutritional deficits result and can cause weight loss, anemia, and aggravate symptoms of the disease.

Therefore it is important that the person with AD and the caregiver eat a well balanced diet to avoid illnesses and cope with the stress of the situation. There may even come a time that the person with Alzheimer's may lose the ability to feed himself, chew or swallow. When this occurs, family members will have to feed the person.

With the exception of a lower calorie requirement, older adults, including those with Alzheimer's Disease, need the same nutrition as they did previously. There are several reasons why they may not eat properly.

For one reason, eating is a social activity, and loneliness can affect the desire for food. Eating with another person as often as possible can help. As people age, their senses of taste and smell decrease. It is important to make food look, smell and taste good. Since many people have a smaller appetite, serving smaller portions more often can help.

Chewing problems because of ill-fitting dentures, no teeth, broken teeth or sore gums can all interfere with a person's ability to eat. It may be beneficial also for caregivers to have the person with Alzheimer's rest before eating, since the task of eating requires energy.

To minimize difficulties at mealtime, caregivers should consider the following suggestions:

1) Make mealtime as quiet and relaxing as possible. Soft music can be calming.
2) Eat at the same time or as close to the same time daily and in the same place.
3) Make sure the person's hands are clean and that dentures are in tight.
4) Cut food into bite-sized pieces.
5) Allow the person to feed him/herself for as long as possible. Use a bib if necessary.
6) Serve finger foods that are easy to handle.
7) Ignore the mess and spills that may occur during the meal. Use plastic tablecloths.
8) Utensils with large, built-up handles of foam or wood help a poorly coordinated person eat independently. Use only the necessary utensils.
9) Do not serve too many different foods on the plate at one time.
10) If the person refuses to eat, the caregiver should begin eating and the person with Alzheimer's Disease often will begin eating also.
11) Use mugs for soups.
12) Make sure the person is not holding food in his mouth before lying down.

As the disease progresses and skills decline, the person may have to be fed all meals. Difficulty chewing and swallowing can develop and the possibility of choking becomes a real issue. Consistency of foods can pose problems to the person. They do not know whether to chew or to drink certain foods (e.g., cereal and milk).

The person with AD can also develop behaviors that can be dangerous, such as taking food from other peoples plates and swallowing it rapidly without chewing well. Caregivers are urged to attend a class on the Heimlich Maneuver.

Exercise and Mobility

Activities of daily living involve the ability to move around safely within the environment while still having a sense of meaning and purpose in life. Daily exercise contributes to the physical and mental health of the person with AD.

Alzheimer's Disease can and does affect the person's ability to function. During the earlier stages of the disease, there is little change in the ambulatory skills, balance or coordination of the person. As the disease progresses, the person develops **apraxia**. Simply put, apraxia is a series of mixed messages sent from the brain to the body. The body does not know how to react to the messages and the person can no longer carry out purposeful movements. He becomes clumsy, unsteady, and awkward when walking.

The potential for falls becomes an issue, especially when the person is performing many normal activities such as shopping, climbing stairs, bathing or getting in or out of the bed or chair.

It is important for the caregiver to allow the person to be as independent as possible and not to intervene unless necessary. Independence, especially in ambulation can do much for the person's well-being.

1) Supervise and structure activities at all times.
2) Encourage participation in household tasks, e.g., folding laundry, drying dishes, etc.
3) Encourage time with grandchildren.
4) If medically permitted, include a short walk daily in the person's routine. Inspect the person's feet regularly for any sore areas.
5) Include the person in family decision making for as long as possible.
6) Allow the person to make his own decisions for as long as they are able.

Safety Tips on exercise and mobility (see also Caregiver Lesson Plan on Safety and Environmental Adaptations):

1) Assess reaction to any new medication (e.g., changes in appetite, mobility, etc.) that the person is started on.
2) As the disease progresses, arthritis and other chronic diseases may compound problems in movement.
3) Encourage the use of canes and walkers as the person's ambulatory skills worsen. Unfortunately the person will reach a point in the disease where they will no longer be able to use the devices.
4) Do not have scatter rugs on the floor. They are hazards to older persons.
5) Make sure the person is wearing snug-fitting shoes with non-skid soles.
6) Do not rush the person with Alzheimer's Disease.
7) Wipe up wet spills immediately.
8) When helping an unsteady person walk, have them wear a wide belt that you can hold onto for safety.
9) Encourage the person to hold onto rails and furniture for support if necessary.

Ambulating with a Cane and Walker

Canes and walkers are specifically measured and fitted for each individual and should never be shared by others. Physical therapists usually will instruct the person on the proper use of the cane or walker. Always check the equipment for worn or missing tips before use. Be aware of safety hazards in the person's path. Be alert to the person becoming overtired.

Cane:

1) Canes can have a single tip or up to four tips for additional support.
2) When coming from a sitting position the person must:
    a) move forward in the seat
    b) lean forward, plant his feet firmly on the floor about a foot apart
    c) with an upward thrust, push him to a standing position while he is holding onto the cane with one hand and placing the other hand on the armrest.
3) The person holds the cane on his stronger side.
4) The cane is moved first, then the weaker foot is moved if there is one and then the other foot. The sequence is then repeated.
5) The cane should be moved 10-18 inches ahead of the person as each step is made.
6) Sitting back down the person must:
    a) turn her back to the chair,
    b) back up to the seat until her legs touch the chair,
    c) hold onto the cane and grasp the armrest of the chair, and
    d) gently ease into the chair while bending at the hips and knees.

Walker:

1) Walkers can have four rubber tipped legs or two front wheels and two back legs.
2) The person must grasp the top of the frame and lift, move it in front of them, put it down, then take a step forward while leaning on the walker for support.
3) When coming from a sitting position the person must:
    a) place the walker in front of him,
    b) move to the edge of the seat,
    c) plant his feet firmly on the floor about a foot apart,
    d) hold onto the armrests while pushing up to a standing position, and
    e) grasp the walker firmly, one hand at a time.

4) Sitting back down the person must:
   a) stand at the side of the chair and turn slowly,
   b) back up until her legs touch the chair,
   c) reach back with one hand and grasp the armrest, and
   d) gently ease into the chair while bending at the hips and knees.

Transferring a Person from Bed to Chair or Wheelchair

During transfer, always be sure that the person wears shoes with nonskid soles. If the person has a weaker side, allow him to lead with his strong side. Get help if you feel the person may be too heavy to transfer alone. Always encourage the person to help if able. Always check the wheelchair for broken or unsafe parts.

The procedure for transferring safely is as follows:

1) Position the wheelchair next to the bed on the person's strong side if he has one, lock the wheels, raise the footrests.
2) Have the person move to the edge of the bed and sit for a few moments (provide assistance, if necessary).
3) Stand in front of the person with feet planted about a foot apart.
4) Bend at the waist, keep back straight, place hands under the person's arms.
5) Have the person place his or her hands firmly around your waist and instruct the person to stand at the count of three.
6) Straighten your legs, help the person to his feet and pivot around toward the chair.
7) Turn until the person is in front of the chair with his or her legs against the seat.
8) Have the person reach for the armrests, take hold and lower him/her into the chair.
9) Arrange clothing, place feet on foot rests.

To transfer back into bed reverse the steps.

Turning a Person in the Bed

To prevent skin breakdown, a bedridden person must be turned at least every two hours. It is possible for one person to turn another safely. When turning a person, follow these guidelines:

1) Have the person lie flat in the bed, cross her arms across her chest.

2) Cross the leg farthest from you over the one closest to you.
3) Reach across the person supporting his shoulders and hips with your hands and arms.
4) Roll the person gently and smoothly to you, place a pillow at his back for support.
5) Pillows can be placed between the knees to prevent rubbing and pressure, especially if the person is thin and bony.
6) Lotion can be applied to the back and other areas of the body after each turning.
7) Readjust the sheets, pillows and bed spread for comfort and neatness.

Conclusion

No matter what the caregiving task entails there are some general guiding principles that are important to follow.

1) Treat each person as an adult individual deserving of respect.
2) Pay attention to each individual's reactions.
3) Maintain dignity.
4) Encourage independence.

AUDIO-VISUAL REINFORCEMENT:

"Keeping Active and Physically Fit" (Unit V - in the series, "Alzheimer's 101: The Basics for Caregiving) produced by South Carolina ETV in cooperation with the South Carolina Commission on Aging. Distributed by SC ETV Marketing, Drawer L, 2712 Millwood Ave., Columbia, SC.

"Helping People With Dementia in Activities of Daily Living" produced and distributed by Michigan Media, the University of Michigan, 400 Fourth St., Ann Arbor, MI 48103-4816. (313/764-8298).

"Managing with Alzheimer's Disease" produced and distributed by Good Samaritan Hospital and Medical Center, AV Services, 1015 N.W. 22nd Avenue, Portland, OR 97210. (503/229-8039).

EXPERIENTIAL LEARNING:

1) At the end of this module are pages which can be used as Caregiver Handouts to stimulate discussion among caregiver participants. Prior to the workshop make copies of the hand-out for each caregiver expected to attend.

REFERENCES AND SUGGESTED READINGS:

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Chenitz, W.C., Stone, J.T., & Salisbury, S.A. (1991). Clinical gerontological nursing: A guide to advanced practice. Philadelphia, PA: W.B. Saunders Company.

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Tanner, F., & Shaw, S. (1985). Caring: A family guide to managing the Alzheimer's patient at home. New York: The New York City Alzheimer's Resource Center.

Morag S. Walden is gratefully acknowledged as the major contributor to this module.

Taking a Trip Away from Home

Remember the person you are caring for typically does not respond well to being hurried. Therefore, when you are away from your home you should not set yourself up for trouble by planning to hurry. The routine sequence of activities will provide a predictable and familiar feeling that will compensate for different surroundings.

The next most important action is to plan **rest times**. Being away from home is taxing for the person with AD. It forces them to think about where they are and what they are doing rather than allowing them to habitually meander. You also will likely find you tire more easily. Make sure you allow for at least one quiet time mid-morning and mid-afternoon; choose your outings and accommodations accordingly. You may find that it is better to rent a hotel room close to relatives rather than staying with them in order to have this quiet rest time regularly. You may find that something simple will suffice to meet this need such as a visit to a little coffee shop or book store to sit for a bit. Use your judgement as to what will provide time for the AD person to unwind, but do make sure you plan this into your day.

In addition, there are some **safety precautions** you should take. In case the person gets lost, carry a recent photo that clearly shows facial features, take note of the person's clothing daily, and make certain the person has some ID. Have your resources ready in case things do not go as well as you had hoped. For example, keep your travel dates flexible in case you wish to come home sooner, and consider asking your physician to write a prescription for some anti-anxiety type of medication.

Often, being away from home can cause the AD person to be more easily confused and somewhat edgy. If you anticipate this and adapt by taking the actions described, you will improve the likelihood that your trip will indeed be enjoyable for everyone involved. Bon Voyage!

From: The Alzheimer's Association (for Educational Purpose Only)

Make Mealtime Simple for Alzheimer's Patients

by Mary Sue Walker
Registered Dietitian

Play soft, relaxing music during meals. Television programs, particularly situation comedies, soaps, dramas and news can cause agitation. An AD patient often cannot distinguish between the reality of the program and his or her immediate environment.

Serve meals at regular times. If your father refuses to eat, simply take the plate away. Return in a few minutes and offer it to him again. Often he will accept it then.

Conversely, your father may not remember that he has just eaten and will want to eat again. Try distracting him with walking or other activities. If this doesn't work, keep low-calorie snacks available such as fresh fruits or vegetables cut in small serving sizes. Even small portions of gelatin desserts may be helpful.

Keep table setting simple. Avoid brightly patterned place-mats and napkins and have only the essentials for eating the meal on the table.

Try using bowls rather than plates and use serving pieces that are a different color from the placemat to help your father find the plate more easily.

Use mugs with big handles for soup.

Try to serve finger foods as often as possible - cheese, sandwiches cut into fourths, boneless chicken pieces, fresh fruits and vegetables.

Bendable straws in drinks make liquids easier to manage.

Make certain that food isn't very hot when served because the AD patient can get burned without realizing it.

Courtesy of Alzheimer's Association - Eastern Tennessee Chapter

Happiness is not created
by what happens to us,
but by our attitudes
toward each happening

Some Common Problems and Basic Care Ideas for Persons with AD

- Approach the person in a friendly, relaxed manner. (If you are hurried, the person may become tense/resistant.)
- Always identify yourself and face the person
- Speak calmly and slowly. (A high pitched tone conveys anxiety and tension.)
- Eliminate environmental distractions. (Confusing)
- Use short simple statements. (Examples: Are you cold? Are you thirsty? Come/Go with me.)
- Ask only one question at a time.
- Break down tasks in individual steps. (Examples: Here is your toothbrush; take it; brush your teeth.)
- Use non-verbal clues.
- Avoid arguing with the person.
- Observe the person's non-verbal behavior. (Since the person is unable to verbalize pain/discomfort, observe for high restlessness/agitation.)

Courtesy of Alzheimer's Association - Southside Chapter

Module 8: Safety and Environmental Adaptations

GOAL: To protect the safety and welfare of the person with AD and decrease the frustration of the caregiver by ensuring a safe and functional home environment.

RATIONALE: Caregivers who provide in-home care to the individual with AD look at the home environment through a different set of eyes. Creating a safe home environment is a primary concern. Simple modifications in the physical environment will help protect the person with AD from needless injuries and enhance successful management of dementia at home.

EDUCATIONAL OBJECTIVES:

1) Explain what it means to "safety proof" the home environment.
2) List nine environmental needs for the person with AD.
3) Name three principles of home safety for the individual with AD.
4) List three behavioral problems that a person with AD may have and discuss how to "safety proof" the environment.

MINI LECTURE:

The home is a very important place for an individual with AD or a related dementia. Familiar surroundings help remind the person of who and where he is and what is expected. On the other hand, as the dementia progresses, once familiar surroundings may become strange, confusing, and potentially dangerous. This deteriorating relationship with the environment can be a source of frustration for the caregiver and the care recipient. However, the interrelationship among the home environment, the caregiver and the person with dementia is an area that has received little attention.

A person with a dementing illness needs to get around as safely as possible. Behavior is influenced greatly by the environment in the early and middle stages of the disease. Though he may be less aware of the environmental hazards (e.g., loose wires, furniture with sharp edges, breakable objects, or scatter rugs), the person is more sensitive to environmental frustrations (e.g., a loud noise, a cluttered home, dim or glaring light, etc.) that may negatively affect his behavior. This lecture focuses on ways to "safety proof" the home environment. It will give suggestions on management of dementia by environmental modifications.

A Definition of "Safety Proof"

Changing the physical environment to make it safer for the individual with AD and others is to "safety proof" the home. These changes give those with AD the freedom to do what they want, and yet be safe for everyone to do the things they have to do.

Simplifying the home environment, removing potential safety hazards from the environment, and installing assistive devices are means of environmental modification. By making environmental modifications, potential accidents or injuries are prevented and specific behaviors are managed more effectively. "Safety proofing" the home is a very important step in providing adequate care.

The source of stress and disruption of daily life is very different for different groups of caregivers. When "safety proofing" the home environment, a balance must be obtained between the needs of the care recipient and the caregiver. Both will benefit from environmental modifications which facilitate their independence and reduce the level of supervision required. Eliminating potential hazards or making minor alterations in the environment will make the home a familiar place of safety and security for the caregiver and person with AD.

Environmental Needs

Certain criteria should be met when "safety proofing" the environment, whether the care recipient is living at home, attending an adult day care center, or residing in an institution. According to Pynoos, Cohen, and Lucas (1988) the surroundings should be designed to:

1. Promote dignity and independent functioning.
2. Provide appropriate sensory stimulation.
3. Provide security and safety for the individual.
4. Provide appropriate level of activity/task.
5. Provide a homelike and familiar atmosphere.
6. Provide for individual control and privacy.
7. Create opportunity for socializing.
8. Be flexible and adaptable in supporting the person's behavioral and physical needs.
9. Emphasize wellness and maintain connection with the healthy and familiar.

There have been few or no checklists available to direct the caregivers in their efforts. To identify changes to make in "safety proofing" the home, problems need to be identified that involve potential hazards for the person with AD.

Go through your home and list potential hazards and dangerous objects. Be alert for things that could cause an accident. One also should keep an eye out for things that the individual with a dementing illness could misinterpret or misuse. Accidents can happen not only because of obstacles or misusing things, but also because the person with AD is no longer able to evaluate the potential consequences of her actions.

Principles of Home Safety

When approaching the task of home safety, remember these general principles.

1. **Think prevention!** It is very difficult to predict what someone with dementia may do. Just because something has not yet occurred, does not mean it should not be cause for concern. Even with the best laid plans, accidents can happen. However, the caregiver can take control of the potential problems by checking the safety.

2. **It is more effective to change the environment, than it is to change most of the behaviors which occur with AD.** While some of the behaviors which accompany Alzheimer's Disease are managed with special medications prescribed by a doctor, many cannot be medically controlled. Since it is possible to make changes in an environment, decrease the hazards and stressors that result from the behavioral and functional changes associated with AD.

3. **By minimizing danger you can maximize independence.** A safe environment can be a less restrictive environment where the person with AD can experience increased security and more mobility.

(Home Safety for the Alzheimer's Patient)

"Safety proofing" the home environment can seem impossible given the changing behavior and needs of the person with AD. Caregivers may fear that resources will be difficult to identify. Sometimes the caregiver may feel that the home is in need of total renovation to deal with the changing needs of their loved one. At other times the caregiver may be uncertain about whether the changes are really necessary. These are instances when the caregiver may need to rely on the more objective opinion of others.

Trusted family and friends can assist with identification of safety hazards and help with the needed modifications. Other local resources, such as a representative of the Alzheimer's Association, area agency on aging, churches, or other agencies may provide these types of services to help you. Their services and assistance encourage environmental adaptations that compensate for dementia impairments.

A concern of many is how to adapt the environment to reflect the individuality of the care recipient and their family. Successful environmental adaptation requires that the surroundings be tailored to the unique needs of the care recipient. The environment must be challenging to the individual's changing levels of functioning, and appropriately supportive. The caregiver also will need to look closely at his own stress level and events that cause disruption, and what is feasible in modifying the home. Finding this balance is an essential part of allowing the care recipient to remain independent.

Environmental Needs of Persons with Alzheimer's Disease

The living environment is extremely important to an individual with AD. **Safety, simplicity and consistency, and reminders** in the surroundings are things that can compensate for the person's losses or diminishing capacities while still meeting his environmental needs.

Safety

Environmental modifications to protect the safety and security in the home are important to all elders. They may be even more important for the older adult suffering from dementia. Forgetfulness and confusion are common characteristics. It is extremely important either to remove all potentially dangerous objects in the home, or safeguard their use. Remove poisonous materials (i.e., cleaning materials, insecticides, medications, etc.) and keep in a safe place. All unsteady furniture should be fixed and unused appliances should be disconnected. Small objects and trailing wires and cords should be shortened or taped down.

Alzheimer's Disease results in poor mobility, coordination, and reception sensory cues; therefore, unnecessary furniture, clutter, and area rugs should be removed. To prevent accidental falls and injury, safety gates should be placed at the tops of stairs. Lighting can be improved in areas that are especially dark or full of glare. Try to get rid of distracting light and bright unshielded light that produces glare. Background noise should be reduced or kept to a minimum to help the person with AD concentrate and decrease their agitation.

Simplicity and Consistency

Simplicity and consistency of home furnishings and decorations further enhance the safety of the environment. Rooms, especially the bedroom and the bathroom, should be well lit and simply decorated. Magazines, clutter and knick-knacks are confusing to the individual who is impaired and should be kept out of reach of the individual with dementia. Furniture should not be moved around and items that the person uses should be kept in a consistent place. Keeping things simple and consistent helps to deter accidents and makes life less perplexing or frustrating for the individual with dementia.

Reminders

Provide clues and notes to enable the person with dementia to function better. Reminders help to orient the individual with a dementing illness to what things are and what is expected. The individual may benefit from writing things down himself in the earlier stages of the disease. As the disease progresses, difficulty remembering can often be handled by making simple, easy to read signs.

Caregivers are sometimes reluctant to introduce changes in the home because of the temporary nature of many behaviors. This hesitancy also may be related to the cost of making the change. Although most of the changes will involve little or no cost, the caregiver must decide the appropriateness and cost of each item. Items often will be available at stores carrying hardware, grocery items, children's items and medical supplies. The small adjustments made, or dollars spent wisely, may ultimately yield substantial financial and psychological savings for the family.

The physical environment offers many opportunities for improving safety. The following items provide a checklist of environmental adjustments you can use to reduce potential risks of injuries in the home. Persons with AD may or may not have these symptoms as they move through the stages of the disease. The suggested safety recommendations may help reduce risks of injury, and give the caregiver some peace of mind since precautions have been taken to prevent hazardous events.

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BEHAVIORAL PROBLEMS THAT THREATEN SAFETY
SUGGESTED ENVIRONMENTAL ADJUSTMENTS

Aggressive Behavior:

The person with AD may exhibit aggressive behavior, become excessively upset, or display rapidly changing moods (See Caregiver Lesson Plan on Managing Episodes of Aggressive or Hostile Behavior). Often they will insult, complain or accuse others of wrongdoing. If the environment is too stimulating (e.g., if there is too much clutter, noise, or activity), arguments or episodes of aggressive behavior (e.g., throwing things, screaming or hitting) may result.

Suggested environmental adjustments:

☐ Keep the home uncluttered.
☐ Reduce stimulation in the environment.
☐ Simplify tasks or activities (e.g., explaining in order what to do or putting items out in sequence).
☐ Have a list of emergency numbers (e.g., fire, police, emergency, or ambulance) by the phone.

Boredom and Inactivity:

The person may lose the ability to think of activities and keep busy as Alzheimer's Disease progresses. Boredom and inactivity may result from confusion, lack of stimulation, or the need for familiar items. These situations may create a need for exercise or simplified activities.

Suggested environmental adjustments:

☐ Involve the individual in activities that are useful (setting the table, matching socks, winding yarn).
☐ Involve the person in any activity of interest that he enjoyed doing in the past.
☐ Create a box filled with items that represent the person's interest from the past.
☐ Keep activities simple and repetitive (e.g., playing cards by matching suits or putting them in piles; raking; or sweeping).
☐ Engage the individual in activities that will orient him to his home and living environment (e.g., looking at pictures).

☐ Provide a real or stuffed animal to serve as a companion.
☐ Involve the person with AD in exercise and calisthenics.
☐ Go for a walk with the person or let him walk around in the backyard or in an enclosed area.
☐ Put on music and consider dancing or singing.
☐ Use interactive art, such as sand painting, or objects that move when you turn them.
☐ Play word games that trigger memory.

Destructive or Dangerous Behavior:

Individuals with dementia may experience rapidly changing moods and become excessively upset when a situation overwhelms them. Too much stimulation in the environment may cause anger, confusion, and frustration. The individual with AD cannot make sense of his environment and lacks the cognitive awareness needed to function (e.g., perceiving, thinking, and remembering). The lack of ability to control temper or moods may cause negative results or reaction. The person may lash out at you or others, become agitated, slam and break things, or become otherwise aggressive.

Suggested environmental adjustments:

☐ Find ways to remove any clutter from the environment (e.g., magazines, papers, clothes, etc.).
☐ Keep home simple. Remove any unnecessary furniture and breakables that you do not wish destroyed.
☐ Remove any hazardous materials to which the person might gain access (e.g., weapons, knives, or poisons).
☐ Reduce extra sounds or noise (e.g., machines or people).
☐ Remove unsteady furniture.
☐ Remove furniture with sharp edges or use bumper guards on edges.
☐ Secure windows so that they cannot be opened by the person. Placing a lock at the top can be helpful.
☐ Block large areas of breakable glass (e.g., china cabinets or sliding doors).
☐ Make sure medications are out of reach and securely stored.
☐ Take knobs off stove and other appliances if possible.
☐ Turn circuit breakers to the off position when not using and secure the fuse box.
☐ Keep child-proof covers over electrical outlets.
☐ Place locks or masking tape on drawers or cupboards you do not want the person to get into.

☐ Remove poisonous flowers or plants from inside the house and supervise activity around those outside.
☐ Remove all matches and lighters.
☐ If the person is a smoker, he should be well-supervised and use a self-extinguishing ashtray.
☐ Smoke detectors should be in good working order at all times, especially in hallways. A fire extinguisher should be in the kitchen or other accessible location. It is important that all members of the house be aware of an emergency evacuation plan.

Eating:

Problems with eating become increasingly apparent in a person with AD as the disease progresses. The person may have a sudden or gradually decreasing need for calories and not be hungry. As the disease progresses, the lack of interest becomes evident. Poor coordination, and loose fitting dentures add to messy eating and the resulting poor table manners. Changes in eating behavior also can result in missing a meal, eating inappropriate foods, or hiding foods.

a. Lack of interest in food and apraxia: Accompanying the aging process is the decreased need for calories and diminishing senses. Problems may become enhanced with depression, constipation or difficulty in chewing or swallowing. In addition, the person with AD also may be confronted with loose dentures, lack of coordination, or memory loss when eating.

Apraxia is the inability to carry out familiar, purposeful movements (e.g., eating) due to sensory impairments. The person may also have difficulty in using objects because they cannot perceive their nature and purpose.

Suggested environmental adjustments:

☐ Present food that is attractive, colorful, and flavorful.
☐ Involve the person with AD in food preparation (e.g., getting pans, rolling dough, or putting trash in the waste basket).
☐ Vary the aromas of food as much as possible to encourage interest in eating.
☐ Play pleasant soothing background music.
☐ Serve one course at a time.
☐ Check the temperature of foods. The person may lack judgment in determining whether something is hot.
☐ Check with the dentist concerning dentures.
☐ Check with the physician about possible depression.
☐ Serve familiar foods. New foods may cause confusion.

b. Overeating or Eating Inappropriate Foods: Due to the memory loss, the person may forget that he just ate and eat again. He may eat out of boredom or may want sweets or other diet restricted foods.

Suggested environmental adjustments:
- ☐ Make meal time a routine.
- ☐ Reduce access to certain foods (e.g., sweets and other restricted foods).
- ☐ Substitute similar foods that are healthy (e.g., artificial sweeteners for sugar and unsweetened cereals).
- ☐ Provide healthy finger food snacks regularly (e.g., carrot sticks).
- ☐ Introduce food related activity (e.g., decorating cookies or stirring the bowl).

c. Poor Table Manners or Messy Eating: The individual may have difficulty handling utensils due to coordination problems, and lack judgment or interest in foods, all of which may contribute to messy eating. He may have difficulty swallowing or his dentures may fit poorly and influence his eating behavior.

Suggested environmental adjustments:
- ☐ Use only one utensil.
- ☐ Check with dentist about fitting of dentures.
- ☐ Use plastic tablecloths or placements for easier clean up.
- ☐ Use sturdy plastic dishes and cups for minimum breakage.
- ☐ Use contrasting dishes and tablecloth to make dishes easier to distinguish from the background.
- ☐ Use eating utensils with built up handles for easier manipulation while eating. Wrapping tape around the handle will serve the purpose or these utensils are available in a medical supply place.
- ☐ Use plates with suction cups to prevent sliding. Plate guards and dividers prevent food from slipping off plate. Other useful items will be available at a medical supply store or catalogues.
- ☐ Allow the person to continue feeding himself by using finger foods.
- ☐ Put plastic cloth or newspapers on floor for spillage.
- ☐ Put rollers on a sturdy desk chair to roll the person closer to the table.
- ☐ Check temperature of food.

Falling:

For older persons, falls are the leading cause of death from unintentional injury in the home. The causes of falling are commonly environmental factors, such as loose rugs, slippery floors, poor lighting, or defects in assistive or safety devices. Many individual characteristics related to Alzheimer's Disease may increase the risk of falls (e.g., difficulty walking, confusion, medications, and changes in gait, posture and balance).

Suggested environmental adjustments:

- ☐ Make sure all furniture in the person's living space is sturdy and comfortable.
- ☐ Secure all loose rugs around edges or remove them completely.
- ☐ Repair or replace torn carpet.
- ☐ Place textured strips or non-skid wax on hardwood floors to prevent slipping.
- ☐ Check hand railings and banisters periodically to see if they are sturdy.
- ☐ Put hand holds by the bathtub or shower. A grab bar which contrasts with the wall is easier to see.
- ☐ Have a secure gate at the top and bottom of stairs.
- ☐ Have a light switch at both the top and bottom of stairs.
- ☐ Put non-skid strips on stairs.
- ☐ Have a light switch by the doorway of each room.
- ☐ Use a night light.
- ☐ Keep a flashlight, light switch, or lamp beside the bed.
- ☐ Use night-lights triggered by darkness.
- ☐ Use recliners and furniture that provide assistance to get up.
- ☐ Put ramps where needed between floors or at entrances.
- ☐ Make sure space is not cluttered and destinations are visible.
- ☐ Place all electric cords close to walls and out of the pathways.
- ☐ Make sure there is a non-skid surface (non-skid strips or rubber mat) on the floor of the bathroom or shower.
- ☐ For more adjustments see section on **Mobility and Strength Changes** under **Impairment of Senses:**.

Hallucinations, Illusions, and Delusions:

A person with a dementing illness may hear, see, feel, or smell things that are not real. These false sensations are known as **hallucinations**. Problems may occur in poor lighting conditions in which the person may believe that they see something that is not there. Individuals may forget that someone they love is dead and talk continually about them. Hallucinations may cause the person to become agitated, call out, or be resistant to help (see Caregiver Lesson Plans on Managing Episodes of Aggressive or Hostile Behavior and Managing Resistive Behavior Associated with ADLs).

An **illusion** means that the person is misinterpreting something that actually exists (e.g., shadows). **Delusions** occur when the individual with AD believes that his thoughts are actually true, when in reality, they are not. For example, some persons with AD become convinced that someone is stealing from them, although there is no objective reason to think so. Delusions may be persistent throughout the middle and later stages of Alzheimer's Disease.

Environmental modifications may help hallucinations, illusions and delusions, but the person may need to be treated with medications or specific behavioral management techniques.

Suggested environmental adjustments:

- ☐ Check environment to see if it is too stimulating.
- ☐ Make sure there is adequate lighting in all stairs, hallways, and frequently used places to reduce shadows. Dimly lit areas may produce confusing shadows or a difficulty in interpreting everyday objects. Keep extra bulbs handy in secure place.
- ☐ Reduce glare by using soft light or frosted bulbs, partially closing blinds or curtains and maintaining adequate globes or shades on light fixtures.
- ☐ Make sure there is no glare from the sun so everyday objects will not be misinterpreted.
- ☐ Notice if there are glare sources coming from magazine pages, highly polished floors or furniture. It may be useful to use non-glare polish or wax, or to reposition the source of lighting.
- ☐ Have a secure gate at the top and bottom of stairs. Play soothing music.
- ☐ Keep background noises down by closing doors where machines are running or turn down the television. The individual with AD may have to be removed from the noise to a quieter, less stimulating area.
- ☐ Keep furniture and wall-hangings in the same place. Vary the environment as little as possible to avoid confusion.
- ☐ Remove or cover mirrors as they may cause confusion or frighten the person.
- ☐ Give the person something to hang onto (e.g., a stuffed animal or smooth fabric) or hold the person's hand while talking to him.
- ☐ The person with AD may believe violent or disturbing television programs are real. These should be avoided as much as possible.
- ☐ Make sure you have access to an exit if the person is aggressive.
- ☐ Write down reminders of information.

Hiding Things/Rummaging:

Many people with AD put things down and can't remember where they put them. Others hide things and forget where they hid them. These behaviors are a sign of memory impairment. It may occur when the person with AD is bored and does not know what to do. Hiding and rummaging can become a safety problem.

Suggested environmental adjustments:

- ☐ Create a special place for the person to freely rummage or sort (e.g., a chest of drawers, a bag of selected objects or a basket of laundry to fold or unfold).
- ☐ Search the home periodically to learn their hiding places and check them regularly.
- ☐ Put valuable items (e.g., important papers, check books, charge cards, jewelry, etc.) things in a safe place.
- ☐ Keep a neat house and remove clutter to limit the number of hiding places.
- ☐ Limit the opportunity for rummaging by closing access to unused rooms.
- ☐ Keep only a small amount of cash available.
- ☐ Secure all dangerous or toxic products behind locked cabinets or very high out of reach of the care recipient.
- ☐ Keep trash cans covered and out of sight.
- habit ☐ Get in the of checking the waste basket before emptying.
- ☐ Check under mattresses and sofa cushions.
- ☐ Look in shoes and in everybody's drawers and closets for lost items.
- ☐ Place the mailbox outside of a fenced-in yard or obtain a post office box. Persons with AD often hide, lose, or throw away mail.
- ☐ Attach a large tag or label to small items to make them easier to find.
- ☐ Provide the care recipient with a small safe box or treasure chest where he may keep special objects.

Impairment of Senses:

The care recipient's ability to interpret what they see hear, taste, feel or smell declines or changes throughout the progression of the disease. Although sense organs may still be intact, a periodic evaluation by a physician will be able to detect changes that may be correctable through glasses, dentures, hearing aids or other treatment.

a. Vision Changes and Visual Agnosia: Many changes may occur in visual abilities. Safety concerns may be caused by alterations in sense of perception and depth. Other visual changes that often accompany aging also may be present (e.g., yellowing and thickening of the lens, weakened eye muscles and constriction of the pupil, a reduction in peripheral or side vision, impairment of color vision for blue, green and violet, and less efficient dark adaptation). Any older individual may need brighter light, bigger print, or the use of contrasting colors to identify objects or judge distances.

Visual agnosia is a condition in which persons with AD lose the ability to comprehend visual images. Although there may be nothing physically wrong with their eyes, a person with AD may misinterpret what they see due to changes in the brain.

Suggested environmental adjustments:

- ☐ Put bright reflector tape on handrails.
- ☐ Increase lighting level.
- ☐ Eliminate exposure to bright unshielded light sources and minimize glare and shadows.
- ☐ Maintain light level consistently throughout rooms, hallways, or entry ways.
- ☐ Eliminate patterns on floors, which may be confusing.
- ☐ Paint a handrail if the hallway or stairs are dark.
- ☐ Outline doors, mantelpieces, and other things an individual may bump into.
- ☐ Paint baseboards dark if the walls are light.
- ☐ Install lights in dark closets.
- ☐ When covering furniture, do not use patterns.
- ☐ Leave furniture in original places.
- ☐ Use decals on patio doors or other sliding glass doors since the glass is difficult to see.
- ☐ Attach outdoor non-skid tape to edges of stair steps to prevent tripping.
- ☐ To outline one level from another (or from one step to the next), mark the edges with black tape.
- ☐ To make it easier to identify dishes or utensils, use a color contrast.
- ☐ Place signs or simple pictures on important rooms.
- ☐ Use large print for reminders and items used to orient the person (e.g., clocks, signs, or calendars). The easiest to read is black print on a white or yellow background.
- ☐ Keep small pets out of walkways because the person may trip over them.
- ☐ Clearly mark medicines with name, date of purchase, how taken, and when taken and keep out of reach.

b. Hearing Changes: People with AD may have presbycusis. Presbycusis is a normal hearing change that occurs with age and affects the ability to hear high-pitched sounds. Presbycusis also makes it difficult to distinguish between sounds and voices when there is too much background noise. Added to these hearing changes, a person with AD may lose the ability to interpret accurately what they hear. The confused brain cannot make sense of the environment. This change in hearing may result in confusion, over-stimulation, suspiciousness or withdrawal.

Suggested environmental adjustments:

- ☐ Reduce too many background noises of appliances, radios, or television as it is difficult for a person with AD to distinguish between these and what he wants to hear.
- ☐ If possible, provide the person with AD a room away from noisy machines (e.g., washing machines, heater, furnace, TV, etc.) where the person can do an activity or hold a conversation.
- ☐ Use draperies, floor coverings or fabric wall hangings to help muffle or absorb equipment noise.
- ☐ Try peaceful background noise to help calm the person.
- ☐ Provide seating arrangements that are conducive to hearing well (e.g., where everyone can be seen or in a circular fashion). Lighting may also play an important part in hearing, if the person is reading lips and needs to see clearly.
- ☐ Use safety devices for the hearing impaired that provide a signal when the telephone rings, a smoke detector goes off, or the doorbell rings.

c. Mobility and Strength Changes: As we age, there is a decrease of strength and muscle fiber that causes reduced mobility, unstable balance, and slow reaction time. The person with AD may be particularly unsteady as the disease progresses. He may become stiff and awkward. Close supervision will eventually be needed as a stooped leaning posture and/or a shuffling gait results.

Suggested environmental adjustments:

- ☐ Keep the environment clean, clutter free, and easy to move around in.
- ☐ Consider installing a ramp with handrails at entrances preceded by stairs.
- ☐ Securely fasten rugs and carpets staples or tacks to prevent slipping or tripping. They should be smooth and flat and free from folds or wrinkles.
- ☐ Use skid resistant mats in the tub to prevent falls.
- ☐ Anchor handrails and grab bars into studs.
- ☐ Keep pathways free of trash, shoes, wires, cords or small appliances.
- ☐ Make sure animal feeding trays are sturdy and kept out of the way.

☐ Use furniture guards on furniture with sharp edges.
☐ Remove furniture that is unsteady (e.g., chairs that can be tipped over, very low coffee tables, or antiques).
☐ Use stable chairs and chairs with high backs, which are not too deep or low and have arms that extend beyond the edge of the seat whenever possible.
☐ Check the lawn and grounds for places that a person may trip, fall or become otherwise injured (e.g., uneven surfaces or walkways, holes in the lawn, fallen branches, thorny bushes, cracked pavement, hoses, or a low clothesline).
☐ Fence in swimming pool with a locked gate to eliminate access. Keep it closely supervised during in-use periods.
☐ Make sure clothing on the person with AD fits appropriately (e.g., not too long or trailing on the floor).
☐ Use well fitting shoes.
☐ Buy shoes with velcro that are comfortable and easy to get into (e.g., tennis shoes).
☐ Avoid use of extension cords. Place lamps and appliance close to an electrical outlet or secure wires.

d. Touch or Tactile Changes: Tactile changes refer to changes in the way a person feels or interprets items when he touches them. These differences may happen later than changes in vision and hearing. The person with AD may no longer be able to interpret feelings of heat, cold, physical pain, or a loss of sensation.

Suggested environmental adjustments:
☐ Remove or eliminate furniture with sharp corners or cover them with pads.
☐ If possible, remove the hot water faucet handle and store it in a convenient place near the faucet.
☐ Provide the care recipient with things to touch or fold.
☐ Avoid scalding tap water by adjusting temperature to 120 degrees. (Most hot water heaters are set at 150 degrees which can cause burns.)
☐ Try foot and hand-massages in warm water for therapy and relaxation.
☐ Color code handles of faucets using red for hot and blue for cold.
☐ Unplug appliances when not in use.
☐ Obtain a thermometer for the bathtub to monitor temperature of bath water.
☐ Place signs on hot appliances (e.g., oven, coffee maker, toaster, crock pots, irons, etc.) that say "DO NOT TOUCH" or "STOP, VERY HOT." Potentially dangerous appliances should not be used without supervision.

e. Smell or Olfactory Changes: A loss or decrease in smell often accompanies Alzheimer's Disease. For example, the person with AD may not associate the smell of smoke with danger. The olfactory differences may occur later than changes in vision and hearing. Providing familiar and pleasant smells may generate associations with past experiences to trigger long term memory.

Suggested environmental adjustments:

- ☐ Provide the person with opportunities to experience a variety of things to smell (e.g., favorite perfume, potpourri, scented soaps, fruits, foods, coffee perking, or outdoor areas).
- ☐ Make sure quality smoke detectors are installed and checked frequently.
- ☐ Keep refrigerators clear of spoiled foods.
- ☐ Place all medications out of reach.

Incontinence and Toileting Behavior:

True incontinence is the body's inability to control the muscles of their bladder or bowel and usually occurs during the later stages. Chronic or acute bladder infections and uncontrolled diabetes may be a cause for true incontinence.

In earlier stages a person with AD may have accidents and soil their clothes for reasons other than true incontinence. For example, they may forget where the bathroom is located. Confusion and clumsiness may result on the way to the toilet or after reaching toilet. The person with AD may not know what to do once reaching the bathroom. He may be confused on the sequencing of toileting activity and be embarrassed to ask. Awkward clothing may stand in the way of undressing or the individual may not be able to find the bathroom in time. Whatever the cause, as the disease progresses the person with AD will lose the ability to use the toilet properly (see Caregiver Lesson Plan on Maintaining Continence).

Suggested environmental adjustments:

- ☐ Use incontinence products (e.g., pads).
- ☐ Place plastic over chair/other furniture that is being used.
- ☐ Place a sign or verbally remind the care recipient to use the bathroom every hour or two.
- ☐ Place a portable commode in the person's bedroom if bathroom is too far away.
- ☐ Use easy to remove clothing (e.g., pull-on elasticized pants, velcro closures, or two-piece exercise suit).
- ☐ Install handrails and grab bars next to the toilet. Secure handrails by anchoring into studs rather than drywall.

☐ Provide a toilet seat raiser with arms if the person has difficulty getting on and off a seat that is too low.
☐ Place simple signs with sequential instructions next to toilet.
☐ Try using a colored, padded toilet seat to call attention to toilet.
☐ Remove toilet seat cover.
☐ Use beds that are easy to get off and on for night-time trips to the restroom.

Memory Loss:

There are three aspects of memory: (1) recent memory, or recollection of events that have occurred in the recent past; (2) immediate recall, or recollections of events immediately following their occurrence; and (3) remote memory, or recollection of events in the distant past. Of these three, the first two are most affected in individuals with AD.

The continual repetition of questions or inability to remember directions reflect the person's loss of recent memory and immediate recall. This difficulty affects the person's ability to learn new material or acquire new skills. Examples of environmental problems that can result from memory loss follow:

a. Unable to find or recognize the bathroom (applicable to other rooms): This environmental problem may be a result of lack of recent recall or lack of ability to tell the difference between rooms. Confusion or disorientation may be present. Hallways and walkways may be dark, adding to the person's confusion. Poor vision may influence the ability to tell rooms apart. The bathroom may be located a distance from the bedroom, and the person with AD cannot complete the trip.

Suggested environmental adjustments:
☐ Label all rooms (especially the bathroom) with a picture and an identifying word on the door.
☐ Increase lighting in hallways leading to the bathroom.
☐ Use strips of reflector tape on the wall from the bedroom to the bathroom.

b. Difficulty in remembering how to use equipment (e.g., telephone): Physical problems (e.g., arthritis or problems with visual acuity) may cause the person with AD to be unable to use equipment properly. Confusion and disorientation may also be present.

Suggested environmental adjustments:

- ☐ Use reminders or written instructions next to frequently used equipment.
- ☐ Attach a direct dialing system to telephone with most needed telephone numbers.
- ☐ Put large numbers on a template placed around the telephone dial.
- ☐ Use an answering machine when you are not at home to receive messages.

c. Failure to recognize or remember familiar events, people, time: Lack of recent recall is a reason that the person with AD may fail to recognize people or remember familiar events or times. Often cues that aid in identification may not be adequate, or confusion and disorientation may be a cause. Other times, there may be too much stimulation in the environment (e.g., noise, clutter, or people).

Suggested environmental adjustments:

- ☐ Display photographs of family and friends.
- ☐ Have friends wear name tags when they visit.
- ☐ Pin up cues of the day's activities. Keep reminders simple and list times that activities will occur.
- ☐ Keep environment consistent.
- ☐ Leave familiar objects such as picture, magazines and furniture in their usual place.
- ☐ Make sure there are adequate cues in the person's room (e.g., bold faced clock and calendar). Mark days off the calendar as they pass.
- ☐ Provide written reminders of chores.
- ☐ Let the person know when you will return home.

d. Losing and misplacing things: The inability to recall recent occurrences may cause the person with AD to lose and misplace things. Confusion or suspicion may be present along with hallucinations, or the care recipient may have a mild form of paranoia.

Suggested environmental adjustments:

- ☐ Keep home simple and reduce clutter.
- ☐ Take away items (e.g., wallet or keys) that can be lost and replace them with non-valuable duplicates.
- ☐ Give the person a special box in which he can keep his items.
- ☐ Go through wastebaskets at the end of the day to see if anything valuable has been accidentally thrown away.

e. Continual repetition of questions: Memory limitations or lack of recent recall may cause the person with AD to repeat questions. Questions may continue out of boredom or insecurity. Another underlying cause may be that he is having difficulty making sense out of the environment.

Suggested environmental adjustments:

☐ Try to be patient with the individual and hold their hand when answering questions.
☐ Introduce an activity or simple task.
☐ Display a reality board (e.g., with date, time, place, and weather conditions) to help person orient himself.

Personal Hygiene:

The person with AD may gradually begin to neglect themselves as the disease progresses. The individual may require total care in the later stages. Problems may arise in getting the person to change their clothes, bathe, brush their teeth, and groom himself.

a. Dressing. Inappropriate choice of clothing or lack of interest in dressing: Multiple choices confuse the person with AD and he may be further confused by the reduced ability to distinguish colors. The person may feel embarrassed by the limitations(s) experienced, or may not show any interest in dressing. The feeling of loss of independence also may result in inappropriate dressing.

Suggested environmental adjustments:

☐ Reduce choices in choosing clothes, colors, and styles.
☐ Make sure tops are matched with bottoms.
☐ Keep the closet and bureau drawers simple by removing clothing that is seldom worn.
☐ Provide a mirror in room for the person to view himself. The mirror may have to be removed if it is disturbing to him.
☐ Arrange clothing by color and in a sequence to aid decision-making.

b. Dressing. Difficulty in remembering how to dress and order of clothes: Memory loss and the lack of coordination may contribute to the care recipient having difficulty remembering how to dress (e.g., button buttons or tie shoes). The physical ailment of arthritis also may be present and may prevent certain actions.

Suggested environmental adjustments:

- ☐ Lay out clothes in the sequence they are to be put on.
- ☐ Use pull-on, two-piece exercise suits or loose clothing for easier dressing.
- ☐ Make sure clothes have velcro closing, front closing, large zippers and no, or only a few, buttons.

c. Bathing. Resistance to bathing: The individual may resist bathing because of a decreased interest in personal hygiene. He may be embarrassed or have a fear of getting in and out of the bathtub. The person may be unable to remember how long it has been since last bathed. Increased fears or phobias about water and bathing activity may inhibit bathing. Indifference and depression also may be present.

Suggested environmental adjustments:

- ☐ Do not leave a severely impaired care recipient in the bathroom alone.
- ☐ Post the bathing schedule on a calendar of daily events.
- ☐ Remove the lock from the bathroom door or deactivate it.
- ☐ Arrange bath items (such as soap, wash cloth, towel, clothes) in the order they are to be used.
- ☐ Check water temperature (keep lower than normal levels) and depth of water in the tub.
- ☐ Place a bench in the bathtub.

d. Bathing. Difficulty with the procedure of bathing: Reduced strength and balance may contribute to difficulty with the mechanics of bathing. The person also may have a fear of falling and slipping in the tub or shower.

Suggested environmental adjustments:

- ☐ Provide hand held shower for ease in washing or long handled bath-brush.
- ☐ Use "soap on a rope" for ease in handling soap.
- ☐ Make sure the floor is non-slippery.
- ☐ If rugs are used, make sure they are fastened securely to the floor.
- ☐ Consider the use of wall-to wall carpeting.
- ☐ Provide bath bench if difficulty in sitting or standing.
- ☐ Install grab bars and skid proof strips on bottom of bathtub or shower.
- ☐ Place a towel on the edge of the bathtub for slippery hands.
- ☐ If bathtub has a glass enclosure, consider removing it for easier access into the tub.

e. Grooming. Difficulty or resistance: Personal care activities (e.g., brushing hair, grooming, putting on make up, oral hygiene, nail care and shaving) should be simplified. They are usually complex and require many steps and should be broken down to support the person's functioning level. The person may be affected by a lack of motor skills, reduced coordination, or chronic limitations (e.g., arthritis). The complexity of the tasks combined with the physical and memory impairments may require the assistance of the caregiver. Other causes such as confusion as to sequence of task, embarrassment and depression also may be present and limit the person's ability to dress and personal hygiene.

Suggested environmental adjustments:

- ☐ Keep the bathroom uncluttered by keeping only the most essential items on hand.
- ☐ Place reminders (e.g., pictures) and simple instructions next to bathroom mirror outlining steps.
- ☐ Arrange items (e.g., brush, comb, and mirror) in order of usage.
- ☐ Use assistive devices if the person has problems gripping or using grooming products because of limited strength or arthritis.

Wandering:

People with AD may wander. It is a common problem at all stages of the disease and deserves attention. Wandering raises more safety and supervision issues for caregivers. It is best described as rambling or roaming aimlessly around without any purpose or defined goal.

Wandering can make it difficult to manage the person at home. Identifying the type and cause will help the caregiver plan a strategy to cope with the behavior. Simple environmental adjustments play an important part to ensure the safety and protection of the person with AD.

a. Constant or agitated pacing in home: Agitation can take the form of pacing or attempting to leave a confined space. Pacing, for many persons with AD, often becomes worse in the late afternoon or evenings. One cause for the constant wandering is that it results from confusion due to the shadows that cause disturbing light patterns. The aimless pacing may be a need for more exercise or may be a side effect of some medication. Wandering may be caused by the person's confusion as the result of boredom or too much stimulation.

Suggested environmental adjustments:

- ☐ Involve the individual in a structured activity around the time that the restlessness occurs.
- ☐ Regulate the light in a room by either providing more light or reducing shadows and glare with adjustable shades on windows.
- ☐ Provide music.
- ☐ Distract the person and involve him in a different more purposeful activity that is appropriate to the functional level of the person.
- ☐ Involve the person in an exercise (e.g., dancing or walking with you).
- ☐ Take the person to another room that is quiet and less stimulating.
- ☐ Provide a platform rocker or other chair that swivels/rocks which may help to relieve restlessness.

b. Leaving home unattended: Wandering may be caused by a need to go to a specific place. The person may have a desire for more exercise or be disoriented.

Suggested environmental adjustments:

- ☐ Install locks that are difficult to open.
- ☐ Display pictures of friends and family members to make the care recipient feel comfortable.
- ☐ Make the person feel welcome in the home by talking with him or sharing tea or coffee.
- ☐ Install locks at the bottom or top of the door where the individual with dementia may forget to look for them.
- ☐ Disguise the door with a piece of fabric that can be attached with velcro to the knob.
- ☐ Put an alarm on the door.
- ☐ Check the home for other means of exit and secure them.
- ☐ Alert police and neighbor.
- ☐ Install a child-proof door knob.
- ☐ Secure large windows so they cannot be used as an exit.
- ☐ Provide the person with a "Safe Return" ID bracelet (available through the Alzheimer's Association; see Caregiver Lesson Plan on Formal Supports and Resources).
- ☐ Provide the person with pocket card with name and address, and with the words "call home" written at the top.
- ☐ Take the person out for regular walks.
- ☐ If the care recipient has just moved to a new home, reassure the person often about where he is and that he is not lost.

c. **Wandering in middle or night:** Wandering in the middle of the night has many causes. It may be caused by too much medication, or the person may be sleeping or napping too much during the day. Too much light in the room may be a cause. Poor lighting may lead to the misinterpretation of dim shapes. The person may have a difficult time separating hallucinations and dreams from reality. Wandering at night also may be caused by too little exercise.

Disorientation also may occur when the person has to go to the bathroom but gets lost because he cannot find the way. At other times he may not know how to handle the mechanics of using the bathroom, become confused, and start pacing as if searching for an answer to his dilemma.

Suggested environmental adjustments:

- ☐ Arrange the bedroom so that the person can move about safely.
- ☐ Increase the individual's activity during the day.
- ☐ Check with the care recipient's physician about the medications he is taking.
- ☐ Install bedrails. If the person tries to climb over them, discontinue use.
- ☐ Attach a bell to the door to alert someone when the door is opened.
- ☐ Install an intercom or monitoring system.
- ☐ Secure stairs by using portable gates at top and bottom.
- ☐ Use night-lights in bathroom and hallway.
- ☐ Use darkening shades on windows to keep out light.
- ☐ Put a portable commode next to the bed.

AUDIO-VISUAL REINFORCEMENTS:

"Alzheimer's Disease: A Delicate Balance" produced by Metro Toronto, Ontario Community Services Department - Homes for the Aged Division, 1990.

"Coping and Home Safety Tips for Caregivers of the Elderly" produced by Commonwealth Films, Inc. Distributed by the Jefferson Area Board for Aging, 2300 Commonwealth Dr., Suite B1, Charlottesville, VA 22901. (804) 978-3644.

EXPERIENTIAL LEARNING:

1) As a group, have participants discuss some of the safety risks they may have in their homes. How would you "safety proof" the home, room by room? What are the other problematic behaviors not mentioned in the module that an individual with Alzheimer's Disease may display? Discuss the related "safety proofing" techniques.

2) At the end of this module are a series of checklists which may or may not be of interest to caregivers depending on which stages of the illness their loved ones are ing. Choose the ones that are appropriate for participants in your group and distribute copies to attendees. Have participants identify precautions they have already taken and those things they intend to do in the future to protect their loved ones from possible harm.

REFERENCES AND SUGGESTED READINGS:

Guide to home safety for caregivers of persons with Alzheimer's Disease. Atlanta Area Chapter Alzheimer's Association, 3120 Raymond Drive, Atlanta, GA 30340 or call (404) 451-1200.

Cantor M. J. (1983). Strain among caregivers. The Gerontologist, 6, 597-604.

Home safety for the Alzheimer's patient. Alzheimer's Disease Education and Referral Center. P.O. Box 8250, Silver Spring, Maryland, 20907-8250.

Mace, N. L., & Rabins, P. (1981). The 36-Hour day. Baltimore: The Johns Hopkins University Press.

Pynoos J., Cohen E., & Lucas C. (1988). The caring home booklet: Environmental coping strategies for Alzheimer's caregivers. Los Angeles, CA: UCLA/USC - Long Term Care National Resource Center.

Jacquelyn Moore Cothran is gratefully acknowledged as the major contributor to this module.

SAFETY CHECKLIST
(Aggressive/Destructive Behavior)

- ☐ Keep the home uncluttered.
- ☐ Reduce stimulation in the environment.
- ☐ Simplify tasks or activities.
- ☐ Have a list of emergency numbers by the phone.
- ☐ Find ways to remove any clutter.
- ☐ Reduce extra sounds or noise.
- ☐ Remove unsteady furniture or pieces with sharp edges.
- ☐ Secure windows.
- ☐ Block large areas of breakable glass.
- ☐ Make sure medications are out of reach and securely stored.
- ☐ Take knobs off stove and other appliances if possible.
- ☐ Keep child-proof covers over electrical outlets.
- ☐ Place locks or masking tape on drawers or cupboards.
- ☐ Remove all hazardous materials (matches, lighters, poisonous flowers or plants, etc.).
- ☐ Supervise smokers and use self-extinguishing ashtrays.
- ☐ Check smoke detectors and keep a fire extinguisher handy.

SAFETY CHECKLIST
(Hallucinations, Illusions, and Delusions)

- ☐ Check environment to see if it is too stimulating.
- ☐ Maintain adequate lighting throughout the house to reduce shadows.
- ☐ Look for sources of glare (magazine pages, tabletops, etc.). Reduce glare from the sun (close blinds), and from objects (use frosted bulbs, globes, non-glare wax).
- ☐ Keep background noises down by closing doors where machines are running or by turning down the television.
- ☐ Keep furniture and wall-hangings in the same place to avoid confusion.
- ☐ Remove or cover mirrors if they cause confusion or frighten the person.
- ☐ Give the person something to hang onto (e.g., a stuffed animal or your hand) while talking to him.
- ☐ Avoid violent or disturbing television programs.
- ☐ Make sure you have an exit if the person is aggressive.

SAFETY CHECKLIST
(Eating)

☐ Present food that is attractive, colorful, and flavorful.
☐ Involve the person with AD in food preparation.
☐ Vary the aromas of food as much as possible to encourage interest in eating.
☐ Serve one course at a time.
☐ Check the temperature of foods. The person may lack judgment in determining whether something is hot.
☐ Check with the dentist concerning dentures.
☐ Serve familiar foods. New foods may cause confusion.
☐ Make meal time a routine.
☐ Substitute healthy foods for sweets and other restricted foods.
☐ Provide healthy finger food snacks regularly (e.g., carrot sticks).
☐ Introduce food related activity (e.g., decorating cookies or stirring the bowl).
☐ Use plastic tablecloths or placements for easier clean up.
☐ Use sturdy plastic dishes and cups for minimum breakage.
☐ Use contrasting dishes and tablecloth to make dishes easier to distinguish from the background.
☐ Use an eating utensil with a built up handle for easier manipulation while eating. Wrapping tape around the handle will serve the purpose or utensils are available in a medical supply place.
☐ Use plates with suction cups to prevent sliding. Plate guards and dividers prevent food from slipping off plate. Other useful items will be available at a medical supply store or catalogues.
☐ Allow the person to continue feeding himself by using finger foods.

SAFETY CHECKLIST
(Toileting Behavior)

☐ Use incontinence products (e.g., pads).
☐ Place plastic over chair/other furniture that is being used.
☐ Verbally remind or take the care recipient to the bathroom every hour or two.
☐ Place a portable commode in the person's bedroom if bathroom is too far away.
☐ Use easy to remove clothing (e.g., velcro closures, or two-piece exercise suit).
☐ Install handrails and grab bars anchored to studs next to the toilet.
☐ Provide a toilet seat raiser with arms if the seat is too low.
☐ Place simple signs with sequential instructions next to toilet.
☐ Try using a colored, padded toilet seat to call attention to toilet.
☐ Remove toilet seat cover.
☐ Use beds that are easy to get off and on for night-time trips to the restroom.

SAFETY CHECKLIST
(Boredom and Inactivity)

☐ Provide useful activities (setting the table, matching socks, winding yarn).
☐ Create a box filled with items that the person has always enjoyed.
☐ Keep activities simple and repetitive (e.g., playing cards by matching suits or putting them in piles; raking; or sweeping).
☐ Engage the individual in activities that will orient him to his home and living environment (e.g., looking at pictures).
☐ Provide a real or stuffed animal to serve as a companion.
☐ Involve the person with AD in exercise and calisthenics.
☐ Go for a walk with the person or let him walk around in the backyard or in an enclosed area.
☐ Put on music and consider dancing or singing.
☐ Play word games that trigger memory.

SAFETY CHECKLIST
(Hiding Things/Rummaging)

☐ Create a special place for the person to freely rummage (e.g., a chest of drawers, a bag of selected objects or a basket of laundry to fold or unfold).
☐ Learn the person's hiding places (e.g., mattresses, sofa cushions, shoes) and check them regularly.
☐ Put valuables in a safe place.
☐ Remove clutter to limit the number of hiding places.
☐ Close and restrict access to unused rooms.
☐ Secure all dangerous or toxic products.
☐ Keep trash cans covered and out of sight.
☐ Check waste baskets before emptying.
☐ Look in shoes and in everybody's drawers and closets for lost items.
☐ Use a lockable mailbox or obtain a post office box. Persons with AD often hide, lose, or throw away mail.
☐ Attach a large tag or label to small items to make them easier to find.
☐ Provide the care recipient with a small safe box or treasure chest where he may keep special objects.

SAFETY CHECKLIST
(Impairment of Senses)

☐ Eliminate exposure to bright unshielded light sources and minimize glare and shadows.
☐ Maintain consistent lighting throughout rooms, hallways, or entry ways.
☐ Eliminate patterns on floors.
☐ Paint a handrail or use reflector tape if the hallway or stairs are dark.
☐ Install lights in dark closets.
☐ Keep furniture in the same place.
☐ Use decals on glass doors that are difficult to see.
☐ Mark the edges of stairs with black tape.
☐ Use contrasting colors to make it easier to identify dishes or utensils. contrast.
☐ Use large print for reminders and items used to orient the person (e.g., clocks, signs, or calendars). The easiest to read is black print on a white or yellow background.
☐ Keep small pets out of walkways.
☐ Clearly mark medicines with name, date of purchase, how taken, and when taken and keep out of reach.
☐ Provide a room away from noisy machines.
☐ Use draperies, floor coverings or fabric wall hangings to help muffle or absorb noise.
☐ Provide seating arrangements that are conducive to hearing well (e.g., where everyone can be seen or in a circular fashion).
☐ Consider installing a ramp with handrails instead of stairs.
☐ Anchor handrails and grab bars into studs.
☐ Keep pathways free of trash, shoes, wires, cords or small appliances.
☐ Remove furniture that is unsteady or unsafe (e.g., "tipsy" chairs, antiques).
☐ Check the lawn and grounds for places that a person may trip, fall or become otherwise injured (e.g., uneven surfaces or walkways, holes in the lawn, fallen branches, thorny bushes, cracked pavement, hoses, or a low clothesline).
☐ Make sure clothing fits appropriately (e.g., not too long or trailing on the floor).
☐ Use well fitting shoes.
☐ Avoid use of extension cords and uplug appliances not in use.
☐ Avoid scalding tap water by adjusting temperature to 120 degrees.
☐ Color code handles of faucets using red for hot and blue for cold.
☐ Place signs on hot appliances (e.g., oven, coffee maker, toaster, crock pots, irons, etc.) that say "DO NOT TOUCH" or "STOP, VERY HOT."
☐ Make sure quality smoke detectors are installed and checked frequently.
☐ Keep refrigerators clear of spoiled foods.
☐ Place all medications out of reach.

SAFETY CHECKLIST
(Memory Loss)

- ☐ Label all rooms (especially the bathroom) with a picture and an identifying word.
- ☐ Use reminders or written instructions next to frequently used equipment.
- ☐ Attach a direct dialing system to telephone with most needed telephone numbers.
- ☐ Use an answering machine when you are not at home to receive messages.
- ☐ Display photographs of family and friends.
- ☐ Give the person a special box in which he can keep his items for reminiscing.
- ☐ Post reminders of the day's activities and chores. Mark days off the calendar as they pass.
- ☐ Display a reality board (e.g., with date, time, place, and weather conditions) to help person orient himself.
- ☐ Leave things in their usual place.
- ☐ Provide a bold face clock and write down when you will return home.
- ☐ Keep home simple and reduce clutter.
- ☐ Replace valuable items (e.g., car keys) with appropriate substitutes (outdated keys).
- ☐ Provide cues to initiate simple activities.

SAFETY CHECKLIST
(Personal Hygiene)

- ☐ Reduce choices in choosing clothes, colors, and styles.
- ☐ Keep the closet and bureau drawers simple by removing clothing that is seldom worn.
- ☐ Provide a mirror in room for the person to view himself, if it is not disturbing to him.
- ☐ Lay out clothes in the sequence they are to be put on.
- ☐ Buy "easy" clothing (pull-on, two-piece, loosely fitting, clothes with velcro or front closing, large zippers and no, or only a few, buttons)
- ☐ Remove the lock from the bathroom door or deactivate it.
- ☐ Arrange bath items (such as soap, wash cloth, towel, clothes) in the order they are to be used.
- ☐ Check depth of water in the tub.
- ☐ Place a bench in the bathtub and provide hand held shower.
- ☐ Use "soap on a rope" and long handled bath-brush.
- ☐ Place a towel on the edge of the bathtub for slippery hands.
- ☐ If bathtub has a glass enclosure, consider removing it for easier access into the tub.
- ☐ Keep only the most essential items on hand in the bathroom.
- ☐ Place reminders (e.g., pictures) and simple instructions next to bathroom mirror.
- ☐ Arrange items (e.g., brush, comb, and mirror) in order of usage.
- ☐ Use assistive devices if the person has problems gripping or using grooming products because of limited strength or arthritis.

SAFETY CHECKLIST
(Wandering)

☐ Involve the individual in a structured activity around the time that the restlessness occurs.
☐ Regulate the light in a room by either providing more light or reducing shadows and glare with adjustable shades on windows.
☐ Provide music.
☐ Distract the person and involve him in a different more purposeful activity that is appropriate to the functional level of the person.
☐ Involve the person in an exercise (e.g., dancing or walking with you).
☐ Take the person to another room that is quiet and less stimulating.
☐ Provide a platform rocker or other chair that swivels/rocks which may help to relieve restlessness.
☐ Install locks that are difficult to open ("child-proof") or located in an unusual place (top or bottom).
☐ Display pictures of friends and family members to make the care recipient feel comfortable.
☐ Make the person feel welcome in the home by talking with him or sharing tea or coffee.
☐ Disguise the door with a piece of fabric that can be attached with velcro to the knob.
☐ Put an alarm on the door.
☐ Check the home for other means of exit and secure them.
☐ Alert police and neighbors about potential wandering.
☐ Secure large windows so they cannot be used as an exit.
☐ Provide the person with a "Safe Return" ID bracelet (available through the Alzheimer's Association; see Caregiver Lesson Plan on Formal Supports and Resources).
☐ Provide the person with pocket card with name, address, and phone number.
☐ Take the person out for regular walks.
☐ If the care recipient has just moved to a new home, reassure the person often about where he is and that he is not lost.
☐ Arrange rooms so that the person can move about safely.
☐ Increase the individual's activity during the day.
☐ Install bedrails. If the person tries to climb over them, discontinue use.
☐ Install an intercom or monitoring system.
☐ Secure stairs by using portable gates at top and bottom.
☐ Use night-lights in bathroom and hallway.
☐ Put a portable commode next to the bed.

SAFETY CHECKLIST
(Falling)

- ☐ Make sure all furniture is sturdy and comfortable.
- ☐ Remove or secure all loose rugs and repair torn carpet.
- ☐ Check hand railings and banisters periodically.
- ☐ Put hand holds or grab bar by the bathtub or shower.
- ☐ Have a secure gate and a light switch at the top and bottom of stairs.
- ☐ Have a light switch by the door way of each room.
- ☐ Put non-skid strips on stairs, hardwood floors, bathtub, and shower.
- ☐ Use a night light.
- ☐ Keep a flashlight, light switch, or lamp beside the bed.
- ☐ Use recliners and furniture that provide assistance to get up.
- ☐ Put ramps where needed between floors or at entrances.
- ☐ Make sure space is not cluttered and destinations are visible.
- ☐ Place all electric cords close to walls and out of the pathways.
- ☐ Make sure there is a non-skid surface (non-skid strips or rubber mat) on the floor of the bathroom or shower.

Module 9: Formal Supports and Resources

GOAL: To increase caregivers awareness of formal supports and resources and to encourage the utilization of these in their communities.

RATIONALE: The most important resource for the older person with dementia is the support offered by family, friends, and neighbors, i.e., informal caregivers. Formal supports and resources exist, however, to supplement and strengthen the efforts of informal caregivers. Many services have been created to meet the physical, social, and emotional needs of the elderly to enable them to remain in the community. Families are strongly encouraged to take advantage of all available services in order to provide the best care possible for their loved ones. Caregiving requires an ability to ask for and accept help and support. It is also important for the caregiver to foster whatever independence is possible and help the person with AD to maintain a sense of self-worth and dignity.

EDUCATIONAL OBJECTIVES: At the end of this module, caregivers should be able to:

1) Understand services based on the Older Americans Act.
2) Follow the seven suggestions given on how to find needed assistance.
3) Identify the appropriate community resources to contact for: a) diagnosis/assessment; b) information and referral; c) legal and financial information; d) support groups and/or counseling; e) home and community-based services; f) special housing, including nursing homes.
4) Consider consulting with a Private Geriatric Care Manager.

MINI-LECTURE:

Certain historical, political, cultural, and economic factors have influenced the outcome of legislation geared toward the nation's elderly. Examples of historical and political factors are:

1) During the 70's and early 80's, aging advocates urged legislators to focus their attention on the need for long term care policy among other pressing needs of the elderly.
2) As the aging network and older adults became more organized, aging advocates gained more political power.
3) In the 70's, policy makers were concerned about creating national policies to achieve family well-being and specifically to improve the well-being of

the elderly and their caring relatives (Palley & Oktay, 1983).

In 1965, Congress enacted the Older Americans Act to assure that the rights and privileges of all older people in our society will be preserved by national, state, and local governments. This Act provided funds to improve the lives of all elderly in need of service. For caregivers and older persons with Alzheimer's Disease, the Older Americans Act protects the right to:

1) Physical and mental health without regard to economic status, and
2) Efficient and readily available community services which provide coordinated social assistance.

A cultural factor that has affected legislation is that the elderly population was, and is still, increasing. An economic factor is rising health care costs. Another economic problem is that many elderly are on fixed incomes, and inflation is eating up their savings. Often those who need the most care are unable to pay for it.

States have developed a variety of concerted responses to these historical, political, cultural, and economic factors. Virginia, for example, has established a Long Term Care Council to support the development of community-based resources to avoid inappropriate institutionalization of the impaired elderly. These community-based services aim to provide a continuum of long-term care services needed to defer institutionalization (Code of Virginia, 1991). Social policies today are moving more toward familial responsibility instead of societal responsibility. Older persons should look at services as rightful entitlement of benefits rather than dependency upon charitable supports that are stigmatized.

Dealing with the maze of formal supports and resources can be frustrating. Caregivers should keep an informal written record, a log, or diary, for recording information about the services that they encounter. The record should include: the name of the person you spoke with, what information was provided, and the phone number and date called. Since it sometimes takes several transfers before referral to the most helpful service provider is made. Patience and persistence are important in this process. The following suggestions will help caregivers cut through "red tape" and find assistance.

(1) **Be specific.** Know exactly what you want before you call a particular agency. Talk to the care recipient, to the doctor, clergy, social worker, etc., and get a clear idea of the type of service you want. If you are unsure of the exact type of agency you need, contact your local Area Agency on Aging. Local Area

Agencies on Aging will refer you or at least suggest which type of agency you can call. To find the number of the Area Agency on Aging that serves your area, contact the Eldercare Locator at 1-800-677-1116. You also have the option of calling your local city or county Department of Mental Health, Department of Social Services or Social Security Administration. There are a variety of national, state, and local resource directories to help caregivers and older adults learn what services are available and where to go for help in your area.

(2) **Be polite but firm.** Do not lose your temper and hang up. Explain your problem or need as clearly and **as often** as necessary. If you are not being understood, try explaining your request in different terms.

(3) **Try to call in the morning or right after lunch.** These are probably the best times to reach case-workers.

(4) **Don't apologize when asking for help.** If your elderly relative or you cannot afford even a minimal fee, say so! Often these agencies receive money through taxes, contributions, and other sources which may pay any charges for the services. Also, some agencies have free volunteer services.

(5) **Get the names of everyone you talk to.** If someone is rude, refuses to help or is impolite, do not lose your temper, remain calm but firmly request to talk to the supervisor.

(6) **If the agency requires an intake interview, be prepared.** Take all relevant legal and financial papers with you. Examples of relevant legal and financial information are: information on the client's resources, insurance policies, living expenses, the client's physician, and health and functional status. You may feel uncomfortable disclosing this personal information. Remember that the provision of these services is costly, and personal information helps determine what portion is paid by you, the consumer. If you feel stressed, take someone along with you. Take notes during the interview and be sure you are clear about what is going to happen and what responsibilities you have, including legal and financial.

(7) **In summary, be assertive,** and you'll get what you want or at least be on the right track.

The following are community resources that may be available to you.

Diagnostic/Assessment Center

These facilities offer testing and a medical assessment of the person who may have Alzheimer's Disease to determine the cause of possible dementia. They also attempt to identify conditions which can be treated to relieve the symptoms. The results of the assessment should be passed on to the person's primary care physician.

Information and Referral (I & R) Sources

A variety of organizations may be able to provide information on Alzheimer's Disease and refer you to the services described in this manual. Available services vary from community to community. To learn what is available in your community, contact your **local Area Agency on Aging** (AAA, pronounced triple-A).

AAAs were formed to develop, coordinate, and provide a wide range of community-based services for the elderly. They are particularly important in rural areas because of the general lack of available services. To compensate, rural AAAs provide almost twice as many direct services than do urban AAAs (Krout, 1991). Yet, the number of services provided by AAAs in rural areas is generally more limited (Krout, 1991; Nelson, 1980, 1983; Taietz & Milton, 1979). Although information and referral (I & R) services are generally available, fewer AAAs in rural areas offer in-home services and adult day care. Rural AAAs typically have smaller budgets and staff, since funding is based on numbers and they serve relatively fewer clients. Since they cover larger territory, more funds are devoted to transportation. Recognizing that rural elders may not often be aware of the community-based services available to them, most rural AAAs offer I & R. Even so, there are persistent obstacles unique to rural areas (such as poor telephone communication systems, larger service areas requiring toll calls, and homes without telephones). These barriers limit knowledge about service availability and necessitate community outreach.

The local AAA may offer some of the services needed, either directly or through sub-contractors. This agency will let you know what is available for persons with dementia, such as respite care, homecare, home delivered meals, and legal and financial advice.

Your **local Chapter of the Alzheimer's Association** is an excellent source of help. To locate your local Chapter, contact the national headquarters. The address is: 360 North Michigan Avenue, Chicago, Illinois (1-800-621-0379 or, in Illinois, 1-800-572-6037).

Discharge and social service units of area **hospitals, local health departments, local Departments of Social Services** may also be familiar with local resources. The doctor of the person with dementia may be able to help you get more information.

Senior center personnel may also be knowledgeable about community services. In rural areas, senior centers may be used by AAAs as service delivery sites. Although senior centers are primarily designed to provide socialization and recreation, they often provide I & R and may offer specialized services. A majority of rural centers offer health screening and education, congregate and in-home meals, and nutrition education. Less than one-third offer homemaker or home health care, and less than 10% offer on-site adult day care (Krout, 1983). Rural senior centers have lower budgets, smaller staff, smaller facilities, fewer activities and services, and fewer linkages with other community agencies (Krout, 1983, 1989). Yet, rural elders are more likely to attend senior centers than those who live in urban areas (Krout, Cutler, & Coward, 1990).

Legal and Financial Information

A diagnosis of Alzheimer's Disease raises a host of legal and financial issues which should be dealt with early in the illness (see Caregiver Lesson Plan on Legal and Financial Issues). Some law firms and individual attorneys specialize in the legal issues confronting the elderly. Some lawyers are experts on the legal and financial implications of Alzheimer's Disease. Although elder law specialists usually list their names in the Yellow Pages under "Wills, Estates, Trusts," it is preferable to get a recommendation from a "satisfied customer." In addition, your local Alzheimer's Association or Area Agency on Aging may have identified lawyers who are knowledgeable about Alzheimer's Disease. They may also hold seminars and workshops. It is very important to consult with your lawyer at the early stages while the person with dementia still has reasonable mental abilities.

Medicare Benefits

The Medicare program has two parts, Part A and Part B. Part A (hospital insurance) helps pay part of the costs of inpatient hospital care, limited care received in a Medicare-certified skilled nursing facility, home health care, and hospice care. You pay no premium for part A coverage, but you are responsible for paying part of the costs -- a deductible and coinsurance charges.

Part B (medical insurance) is designed to cover physician services, outpatient hospital care and lab services. There is a monthly premium for Part B coverage, which is either billed quarterly or deducted from your Social Security check. For your monthly premium, Medicare Part B will pay part of the costs of:

- Physician Services
- Outpatient hospital services
- Outpatient therapies (speech and physical therapy)
- Laboratory tests
- Medical equipment
- Ambulance service
- Outpatient mental health services
- Mammography screenings every other year
- Limited coverage for dental surgery and the services of a chiropractor, podiatrist, and optometrist

Private Supplemental Insurance

Purchasing a good Medicare supplemental insurance policy (i.e, a "Medigap" policy) is one way to fill the gaps in Medicare coverage. Medigap insurance reduces what you pay out of your own pocket for health care services. Private supplemental insurance policies vary considerably, but may also include coverage for non-Medicare items such as prescription drugs, special care (vision, dental, or hearing), and routine exams. Sometimes the difference between your doctor's bill and the Medicare-allowed amount is covered. They often cover deductibles and coinsurance payments. In general, "dread disease" insurance policies (e.g., cancer policy) are not as good a choice as more extensive policies. Long term care policies should be carefully scrutinized to see if they cover supportive services (e.g., personal assistance and other "non-medical" services).

Before purchasing a supplemental insurance policy, check with your State Insurance Commission for information to help you compare the various supplemental policies sold in your state. In almost all cases, you should purchase just one supplemental policy to fill the gaps in Medicare coverage.

Medicare covers home health care on a part-time or intermittent basis if beneficiaries meet restrictive eligibility requirements. The beneficiary must be homebound, in need of skilled nursing care or physical or speech therapy.

Services must be ordered and regularly reviewed by a physician.

Programs To Assist Low Income Persons

The state may pay some or all of Medicare premiums, co-payments and deductibles for persons who are poor and elderly or disabled. Federal law requires that State Medicaid programs pay Medicare costs for **certain** elderly and disabled persons with low incomes and very limited assets. Specifically there are two programs to help people pay their Medicare expenses. One is called the **"Qualified Medicare Beneficiary"** or **QMB** program. It is targeted to people whose resources are at or below the national poverty level. It covers the insurance premium, coinsurance and deductibles people usually pay out of pocket. It does not cover any items that would not normally be covered by Medicare (e.g., routine physicals, dental care, hearing aids and eye glasses). To qualify for QMB, one must be entitled to Medicare Part A, have resources do not exceed $4,000 per person or $6,000 per couple, and whose income is not more than $33/month per person or $840 for a couple (1994 allowances).

The second program is called the **"Specified Low-Income Medicare Beneficiary"** or **SLMB**. It is for persons whose income is slightly higher than the national poverty level but not more than 10% higher. It pays the monthly premium on Medicare Part B but the client still pays the deductibles and co-insurance. For SLMB, the limits are $695 income per month with $4000 resources per person or $923 with $6,000 in resources for a two person family.

Medicaid is a joint federal/state program that pays for health care for people who otherwise might not be able to afford it. Medicaid differs from Medicare because eligibility for Medicaid depends on having very low income and assets. Once eligible, Medicaid provides more kinds of benefits than does Medicare.

To be eligible for Medicaid, you must "spend down" your assets (e.g., use up your own savings). This frequently happens after a person enters a nursing home as a private pay patient. Medicaid law allows beneficiaries to keep a modest amount in community assets and income in order to prevent the spouse at home from becoming impoverished.

Because Medicaid is a joint federal/state program, the laws governing eligibility and benefits vary from state to state. More information is available from your Area Agency on Aging, legal services provider, Medicare/Medicaid Assistance Project (MMAP) counselor, or social service agency (usually your county or state department of social or human services).

Supplemental Security Income (SSI) is a federal program run by the Social Security Administration which provides monthly cash benefits to the aged, blind and disabled with limited income and resources. (It is **not** Social Security, which is based on prior work history and funded through taxes which are paid into it by workers and their employers). SSI is **not** associated with health benefits (like Medicare, Medicaid, QMB, and SLMB) but it is a cash benefit for eligible persons to meet their needs (food, heat, etc).

In summary, for questions concerning Medicare or SSI (federal programs), contact your local Social Security Administration. Your "one stop" for questions and eligibility criteria pertaining to Medicaid, QMB or SLMB (federal/state programs) can be answered by your local Department of Social Services.

Health Care Powers of Attorney and Living Wills

(Also see Caregiver Lesson Plan on Legal and Financial Issues)

A Health Care Power of Attorney (also called Medical Power of Attorney or Health Care Proxy) is a written document authorizing someone you name (your "agent" or "attorney-in-fact") to make health care decisions for you in the event you are unable to speak for yourself. The document can also contain instructions or guidelines you want your agent to follow.

A Living Will is a written statement of your wishes regarding the use of any medical treatments you specify. The statement is to be followed if you are unable to provide instructions at the time the medical decision needs to be made. Living Wills have been recognized by law in most states, but they are commonly limited to decisions about "life-sustaining procedures" in the event of a "terminal illness."

The Health Care Power of Attorney is different from and more flexible than the Living Will in THREE important ways:

1. A Health Care Power of Attorney establishes a person to act as your agent if you cannot act, but a Living Will does not. At the time a decision needs to be made, your agent can participate in discussions and weigh the pros and cons of treatment decisions according with your wishes.

2. The Health Care Power of Attorney applies to all medical decisions, unless you decide to include limitations. The Living Will normally applies only to particular decisions near the end of your life.

3. The Health Care Power of Attorney can include specific instructions to your agent about any treatment you want done or want to avoid or about whatever issues you care most about.

In Virginia, both the Living Will and Health Care Power of Attorney can be combined in one document (see example at the end of Caregiver Lesson Plan on Legal and Financial Issues).

Family Support Groups and Individual or Family Counseling

Family support groups are a good source of information. Most Alzheimer's Association Chapters offer them on a regular basis. Support groups are composed of the friends and relatives of persons with Alzheimer's Disease. They meet regularly to share information and discuss common problems. They are a good source of information about the disease and about resources available to persons with Alzheimer's Disease and their families. They also offer caregivers a chance to give and receive encouragement, support and understanding from others coping with similar difficulties.

The Alzheimer's Association has been very active in helping to organize family support groups. Others have been started by social service agencies, adult day care programs and Geriatric Assessment Clinics which perform diagnostic evaluations.

Counseling is provided by private practitioners or in clinic settings and is recommended for those who find that emotional support from family and friends is just not enough. For those who prefer one-on-one, rather than group, help individual counseling is ideal. Area Agencies on Aging and local Community Service Boards may sponsor free counseling services, and community social service agencies may have counselors on staff. The local Alzheimer's Chapter may be able to recommend specialists who work with family members of persons with Alzheimer's. Your doctor may also be able to refer you to a competent counselor.

Help is also available to persons in the early stages of the disease. Those who are depressed may be helped to understand, accept and deal with the diagnosis, and better plan for the future. Family counseling is also available, and should be provided by trained family therapists. Referrals can be obtained from the sources mentioned above.

Home and Community-Based Services

Persons in the middle stages of AD can no longer survive alone in the community. The person may be unable to remember even basic safety rules. Daily activities such as cooking, driving or using appliances become dangerous. The care-recipient requires close supervision. This part of caregiving can be very difficult and will most likely require services which come to the home.

Here is a list of people and places you may contact about home care: (See yellow pages of phone book under social service organizations, community services, home health agencies or state or local government offices.)

* Alzheimer's Association Chapter (For a referral to the Chapter nearest you, call 1-800-621-0379.)
* Other people who have used home care (Seek referrals from Alzheimer's Association Chapter support groups and help lines.)
* Home health agencies
* Health care professionals (doctors, nurses, etc.)
* State Unit on Aging/Area Agency on Aging
* Local or county public health and welfare departments
* Visiting Nurses Association
* Senior centers
* Nursing homes
* Hospitals (departments of geriatrics, patient education, human resources, and public relations)
* Local churches, religion-affiliated service agencies (Catholic Charities, Jewish Family Services, Pastoral Counseling Services)
* Universities/colleges (gerontology department, nursing school)

Respite Care

Respite is relief for caregivers from the demands of providing constant care. Respite can be provided from a few hours a week to several months a year. It may be offered by volunteers from a local church, synagogue, or senior citizen center, or by the paid staff of homecare agencies or nursing homes with visiting resident programs. The service can be free or costly, long-term or short, and is provided by a variety of organizations. Respite can be provided during the entire course of the disease. The person with Alzheimer's disease may be able to be maintained in the home for a longer time with the help of respite.

There are many benefits of respite care. The caregiver gets relief by having others respond to the care recipient's intense dependency needs. Not surprisingly, periodic separations can help prepare the caregiver for the eventual separation due to long term care placement or death. Furthermore, the mental and physical health of the caregiver may actually improve. Importantly, nursing home placement may be delayed if the caregiver becomes more capable of providing extended care by arranging for periodic time away from the caregiving situation.

There are several types of respite care that families should take advantage of. Adult day care, in-home care, and short-term residential care are becoming more available in rural areas and other communities. Caregivers owe it to themselves and their care recipients to consider these respite options.

Adult day care offers a safe and familiar environment and a structured program of activities for the person with Alzheimer's. It also provides relief from caregiving for the family. If the care recipients start attending day care early in the course of the disease, they may adjust better. It is best if attendance is frequent and regular. If the person objects, the caregiver can gently but firmly insist, while reassuring that he will return for the person later in the day. Although the design of adult day care programs varies, participants ordinarily attend for several hours a day, up to five days a week. Many adult day care programs are not designed for, and will not accept, persons in the middle stages of Alzheimer's. Most will accept persons in the early stages of the disease when their care needs are not extensive. Finally, a small but growing number of adult day care programs are being established specifically for persons with Alzheimer's Disease and related disorders. Adult day programs are not particularly accessible to rural caregivers. Approximately one-third of the AAAs in rural areas do not offer any adult day care programs (Krout, 1989). Many of the programs which exist are located in large towns or small cities that may be some distance away from those who would otherwise use them. Local Alzheimer's Chapters, Area Agencies on Aging and family support groups can help caregivers identify local programs.

In-home care enables individuals with dementia to be cared for in their familiar environment. Agencies who are recommended by others are a good place to start. Use agencies which routinely perform a criminal record check of employees. Check your home insurance policy to establish liability coverage, and inquire about what protection the agency provides their workers. Place your valuables in a safe place and do not keep large amounts of money in your home. Find out if there is state licensing for home care agencies. If so, use those agencies that are licensed. Medicare or Medicaid certification indicates that agencies meet federal standards. As caregivers, be realistic in your expectations of in-home helpers, and consider relatives and friends who may be able to provide services or "swap" afternoons of caregiving.

Home care is the term generally used to describe a host of different services provided to disabled persons in their homes. Many families find they can maintain a person with Alzheimer's at home longer if they have in-home assistance in caring for the person. Services range from supervision and help with household maintenance and meal preparation to the provision of such specialized health services as nursing care, speech therapy and occupational therapy. Home care services are provided by Area Agencies on Aging, Visiting Nurse Services, hospitals, municipal or county Departments of Social Service and a variety of other public, non-profit and profit-making agencies. Some services are covered by Medicare, Medicaid, and private insurance (Medigap coverage), while others must be paid for privately.

In Virginia, many different agencies provide home care. Most of these agencies are listed in your phone book (Yellow Pages) under Home Health, Hospitals, or Nurses. Local Departments of Health, Social Services, and Area Agencies on Aging provide home care, and can help you locate home care services available in your community.

Short-term residential care allows caregivers to place a loved one in a nursing home for a period of time ranging from one weekend to one month. In this way, caregivers can take a vacation or tend to their own needs and be assured that an AD loved one is being properly cared for. Prior arrangements must be made with the nursing home or adult care facility. Different facilities have different criteria such as having a current physical, ordering medications to be dispensed from the facilities' pharmacy, having a chest X-ray or TB test, etc. It is therefore best to contact the facility as much in advance as possible to make sure everything gets done appropriately.

Home Delivered Meals

Persons with AD who are unable to shop for or prepare their own meals may arrange for a hot, nutritious meal to be delivered to them at home. Home delivered meals are provided to eligible elderly up to six days a week by many Area Agencies on Aging. AAAs typically contract out to non-profit agencies for their clients (i.e, persons 60 years of age or older, homebound, unable to prepare meals, with no one to prepare meals for them). Churches and other non-profit agencies, i.e. Meals on Wheels, provide home delivered meals also. A contribution is generally suggested for each meal, and an assessment is conducted to ensure that the service is suitable for the person with the disease.

Safe Return

To more quickly find persons with Alzheimer's who wander, the Alzheimer's Association has developed a program that is specifically designed to assist in locating lost persons with AD and reuniting them with their families and caregivers. Memory impaired individuals registered in the Safe Return Program will wear identification (ID) bracelets with the program's identifying logo on the front. On the back of the bracelet will be the individual's first name or nickname, the words "Memory Impaired," an identifying code number and a 24-hour toll free telephone number (1-800-733-9596). Each participant's personal code number, description, and other pertinent information will be stored in the central registry. Registrants also receive a logo patch to be worn on their outer clothing and iron-on labels with the same information found on the back of the bracelet. The bracelet, patch, and labels help law enforcement officers, hospital workers, ambulance personnel and others to return individuals with AD to their residences and caretakers as quickly as possible.

Special Housing

The types of special housing for the elderly vary widely. "Life care" or **continuing care retirement centers** are the most comprehensive arrangements. They provide a range of housing and services from independent apartment living through full skilled nursing care. This array of services is usually grouped together on a single "campus," easing transitions from one level of care to the next as the needs of the individual change. The financing arrangements for such programs vary. Usually, an initial lump-sum payment is followed by monthly payments which may change over time. "Congregate care" (**homes for adults or board and care homes**) refers to housing arrangements in which older persons live in individual apartments, but selected services are available to residents. These may include meals, social and medical services, and supervision. **Foster, domiciliary, and personal care homes** generally offer room and board with some supervision. Licensing of facilities varies from state to state. Housing options for the elderly are limited in most communities. Current government policy has produced major cut-backs in construction of federally supported housing for the elderly.

Nursing Homes

Many families are eventually unable to care for relatives with Alzheimer's disease at home, even if extensive support is available. Nursing home placement often becomes the most appropriate and responsible care option for persons in the later stages of the disease. At this point, the care that is required may be more demanding and skilled than the family can provide. Most states have strict admission procedures and long waits for beds. Most states have two kinds of nursing homes: skilled nursing and intermediate care facilities:

1) Skilled nursing care is provided for people who need intensive, 24-hour-a-day care and supervision, and

2) Intermediate nursing care is provided for people who do not require skilled, round-the-clock care, but who typically need some nursing assistance and supervision.

Family members can contact state or national associations of nursing homes for information. Many Area Agencies on Aging offer assistance with nursing home placement. This is also a major function of hospital discharge planning units.

Before visiting nursing homes, get information about available options from as many different sources as you can find. Professionals in the long-term care field (such as the ombudsman at the local AAA or state unit on aging) and your friends or acquaintances who have been in a similar situation should be consulted. Church members, your pastor, rabbi or priest, or other trusted friends in your community can also help in your search for a nursing home.

Families find placement of a loved one in a nursing home difficult, even when it is clearly in the best interest of the person and other family members. THE CARE RECIPIENT IS NOW A VERY DIFFERENT PERSON WITH VERY DIFFERENT NEEDS. Families may need to be reminded of the very positive aspects of nursing home care. Round-the-clock professional care relieved by eight-hour shifts may be preferable to 24 hours of care provided by tired, unrelieved family members.

Planning ahead is one of the best ways to ease the stress that accompanies choosing a nursing home. Once you decide that nursing home care is needed, you may become overwhelmed. It is normal to be anxious, angry, guilty, depressed, or scared at the thought of making such a big decision for your family member.

Special Care Units for AD patients

Over the past decade there has been a dramatic increase in the number of special care units for individuals with Alzheimer's Disease and related disorders. These units have proliferated throughout the United States, despite a lack of consensus regarding their characteristics and possible effectiveness.

Special care is designed to maximize functioning and quality of life through the use of specially trained staff, specially adapted activities, and a supportive environment. Special care programs and services may be provided in special care units. Such programs and services are appealing to caregivers who want the most appropriate care for the individual with dementia. Many complex issues are involved in developing public policy regarding special care units. The lack of standards for these units means consumers have no assurances about what, if any, special care a facility provides.

The Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) recently surveyed all nursing facilities (NFs), homes for adults (HFAs), adult day care centers (ADCCs) and hospitals in Virginia (Commonwealth of Virginia, 1993). The survey revealed great diversity among programs in costs, charges and staffing levels. The difference in costs for hospitals and NFs compared to HFAs is attributed to regulatory requirements for staffing, training, equipment and other health related items. Much of the variation can be attributed to differences between the types of services and the facilities providing the services. By contrast, there was more consistency among programs concerning admission and discharge criteria, types of patient activities, programs, the extent of family involvement, procedures to control "disruptive behavior," and physical design of the unit. Statewide surveys of special care units, special programs, and specialized services represent an important first step in assessing the current status of special care. The data uncovered are helpful in guiding the future course of public policy on this complex issue.

The gerontological literature has recently included descriptions of special care units (SCUs) for persons with Alzheimer's Disease (Brower, 1993; Holmes, Teresi, & Monaco, 1992; Mace, 1989). These SCUs separate persons with Alzheimer's Disease and the staff who care for them, from the other residents of the long-term care facility. They are often constructed with environmental modifications intended to permit wandering, support patient functioning, and decrease sensory overload while providing enough environmental cues to encourage orientation (Mayers & Block, 1990; Walker & Marchand, 1990). Environmental modifications aimed at reducing noxious or confusing stimuli might include removing prints and patterns from floors, walls, and furniture, or covering floors with carpet to reduce glare. Intercom systems and mirrors are also frequently removed to keep extraneous noise and frightening reflections to a minimum.

Debate exists about whether SCUs for people with AD are beneficial (Leon, Potter, & Cunningham, 1991; Sand, Yeaworth, & McCabe, 1992). Those individuals who oppose SCUs state that confused patients remain better oriented and function at higher levels when residing with nondemented patients (McCracken & Fitzwater, 1990). Proponents of SCUs disagree with this contention. They point out the disadvantages, to both the confused and nonconfused residents, of integrated facilities such as invasion of privacy, disrupted sleep patterns, and increased numbers of socially unacceptable behaviors (Millard, 1989). Still other issues include: 1) the cost of SCUs (Straley & Cameron, 1991), 2) the need for special training and/or regulation to care for persons with AD (Carley, 1992), 3) the potential stress to staff in caring exclusively for these individuals (Wilson & Patterson, 1988), and 4) questions about appropriate patient mix (Riter & Fries, 1992).

Private Geriatric Care Managers

A growing number of professionals are offering private case/care management services designed to help caregivers locate and coordinate social services. Each care management organization operates differently, but typically the organization will evaluate the older person's situation, make recommendations, arrange appropriate services and keep family members informed. Private care management organizations are frequently listed in the Yellow Pages under Social Services, Social Workers, Aging Services, Senior Citizen Services and Home Health Organizations. To get a referral to a care manager in your area, contact the National Association of Private Geriatric Care Managers at 655 North Alvernon Way, Suite 108, Tucson, AZ 85711, telephone 602/881-8008.

Many communities have more than one agency providing the services you may require. You should compare the services of the different providers. A check list can help you begin your comparison. Since your needs are specific and personal, you will have to add any services that you think are essential.

Note to trainers: *At the end of this module is a checklist that will help caregivers consider their needs for formal supports and resources in an organized way. Distribute the handout and briefly review the rating categories.* Trainers should offer the names and phone numbers of community agencies which provide some or all of the supports listed. Strongly suggest that participants investigate service agencies before they actually need to use the help available.

AUDIO-VISUAL REINFORCEMENTS:

"Supporting Caregivers and Families in Rural Settings" (video in the series, "Building on Strengths: Caring for Elders in Rural Settings, V0258) produced by the Northwest Geriatric Education Center, 1910 Fairview Avenue E., #203, Seattle, WA 98102 (206) 685-7478.

"The Needs and Challenges of Rural Elderly and Their Families" (video in the series, "Building on Strengths: Caring for Elders in Rural Settings, V0256) produced by the Northwest Geriatric Education Center, 1910 Fairview Avenue E., #203, Seattle, WA 98102 (206) 685-7478.

EXPERIENTIAL LEARNING:

1) At the end of this module is a **rating chart** which will help caregivers evaluate and select a nursing facility. Distribute the chart and provide participants with the names and phone numbers of facilities in the community. Encourage caregivers to contact whichever nursing centers they may be interested in, and complete the chart. Strongly suggest that participants investigate these facilities even if they are not ready to make a placement for their loved one at this time. Remind them that some nursing homes have long waiting lists and explain the advantages of making contact early.

2) At the end of this module is a **list** of community resources and services that may be available. Distribute the handout and discuss each of the organizations/supports listed. Ask participants to list the advantages of accessing the each service. It would be helpful to provide relevant phone numbers and encourage participants to investigate the opportunities they may want to consider now or some time in the future.

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"How to Select a Nursing Facility" - Planning Makes the Difference.

The rating chart below has been created to help you evaluate and select a nursing center objectively. By taking the time to use it, you will make a better decision.

SELECTION CRITERIA For each category, write a number - a "2" for outstanding; or a "1" for acceptable; or a "0" for unacceptable.	NF #1	NF #2	NF #3
APPEARANCE AND GENERAL ATMOSPHERE Does it have a homelike atmosphere? Pleasant? Comfortable? Attractively furnished? Are the residents well groomed and neatly dressed? Are their accommodations clean and comfortable? Are the grounds well cared for?			
THE NURSING STAFF Are the nurses and staff members friendly and courteous? Are they attentive and conscientious? Is there high staff morale? Do they enjoy their work? Show a caring, positive attitude? Does the nursing center offer career growth opportunities to enhance the quality of their services?			
REHABILITATIVE SERVICES Do they offer a variety of rehabilitative services? Short term and extended care? Post operative and chronically ill treatment? Physical therapy? Speech and occupational therapy, audiology? Latest equipment? Professional, licensed therapists? Psychological services? Are they approved for Medicare?			
RECREATIONAL THERAPY/ACTIVITIES PROGRAM Individual and group activities? Social events? Holiday celebrations? Arts and crafts? Reading and letter writing? Trips and concerts? Visits home? Games? Volunteer visiting programs? Monthly published social calendar?			
DIETARY SERVICES Offer nutritious and appetizing meals? Between meal snacks? Registered dietician? Special diets? Patients seem to enjoy food? Good kitchen facility? Are meals served in the dining room?			
SPIRITUAL PROGRAMS Regular religious services? Youth and adult group visits? Bible study? Positive, uplifting atmosphere? Community pastors' programs? Group counseling? Goal planning sessions?			
SECURITY Is the facility safe? Fire resistant? Meets or exceeds local, state, and federal fire safety requirements (ask to see current Fire Safety Inspection document)? Are there fire drills and around-the-clock fire safety procedures?			
ODOR Is there an odor problem?			
ADD SCORES AND COMPARE TOTALS			

A list of community resources and services is given below. For each item listed, indicate whether it is available in your community, why it is important, and pertinent contact information (e.g., address and phone number).

1) DIAGNOSTIC/ASSESSMENT

2) I & R SOURCES

Area Agency on Aging

Alzheimer's Chapter("Safe Return")

Dept. of Social Services

Senior Center

Others

3) LEGAL INFORMATION
(Advance Directives)

4) FINANCIAL INFORMATION

Social Security Administration
(Medicare, SSI)

Dept. of Social Services
(Medicaid, QMB, SLMB)

5) COUNSELING/SUPPORT GROUPS

6) COMMUNITY-BASED SERVICES

Respite(Adult day care, in-home care, short term residential care)

Home-Delivered Meals

Others

7) SPECIAL HOUSING

Continuing Care Retirement Centers

Homes for Adults

Foster/Domicilliary/Personal Care

Nursing Homes(Special Care Unit?)

8) PRIVATE GERIATRIC CARE MANAGER

The checklist shown is designed to help caregivers compare service agencies in terms of the help that is available. You should investigate the services listed even if you are not yet in need. When the time comes you will be prepared and know where to go for assistance.

AGENCY	Agency #1 Name Phone Address	Agency #2 Name Phone Address
TYPE OF SERVICE	YES - NO Hours/Days Available	YES - NO Hours/Days Available
Skilled services		
Home Support Services: Bathing		
Dressing		
Walking		
Shopping		
Meal Preparation		
Light Housekeeping		
Other		
COST		
Skilled services: Cost per visit?		
Home Support Services: Cost per visit?		
Total Cost per visit?		
Accept Medicare/Medicaid?		
Covered by personal insurance?		
Waiting Period for Service?		

Module 10: Managing Episodes of Aggressive or Hostile Behavior

GOAL: To increase knowledge and understanding of aggressive episodes in people with dementia or AD, and to apply appropriate interventions to prevent, reduce or diffuse them.

RATIONALE: Caregivers who understand the causes of aggression will be better able to prevent, reduce, or diffuse episodes of aggressive behavior, and to protect themselves and their care recipients from harm.

EDUCATIONAL OBJECTIVES: At the end of this module, caregivers should be able to:

1) Explain why progressive dementia and related feelings may contribute to aggressive behavior;
2) Describe a catastrophic reaction and list three examples (or types);
3) List personal, situational, and environmental triggers (at least three each) of aggressive behaviors;
4) Describe the five stages of aggression;
5) Describe at least three interventions to prevent, reduce, or diffuse an aggressive episode;
6) Describe the "protection priority."

MINI-LECTURE:

It has been estimated that only about 10% of people with AD develop aggressiveness as a result of neurological decline; however, for the caregivers of that 10%, managing behaviors such as hitting, cursing, sexual grabbing, door slamming, etc., can be challenging indeed. It helps to understand what causes these outbursts since many aggressive episodes are predictable and preventable.

First and foremost, the aggressive act is usually NOT a personal attack on the caregiver, but results from a frustrating event or situation. An aggressive act is often triggered by some factor (personal, situational, or environmental). Emotions (such as anger, frustration, and irritability) mount until they hit the crisis stage and explode in verbal abuse (profanity, name calling, sarcasm, threats, etc.), physical abuse (hitting, kicking, slapping, intimidating, etc.), or other acts of aggression (slamming the door, ripping up mail, etc.). After the episode, the emotions de-escalate and the care recipient goes back to his baseline of "normal" (for the particular individual) behavior, or post-crisis depression sets in. To summarize, the stages of an aggressive episode are: **(1) trigger, (2) escalation, (3) aggressive crisis, (4) de-escalation, (5) post crisis baseline or depression.**

In trying to tease out the elements of the aggression cycle, the caregivers must remember that because persons with dementia have little insight into their illness, they do not understand why their activities have been limited. ("What do you mean I can't drive? I've been driving since I was 16!") As the disease progresses, the following changes may occur and impact behavior.

1) Impaired judgment, combined with memory loss and the decreased ability to carry out simple tasks (e.g., lock the door), may result in unsafe situations for the care recipient and others.

2) Frustration with the ever increasing losses can make even the meekest and most compliant person desperate and aggressive.

3) A highly stimulating environment can contribute to explosive behavior.

4) Emotional agitation increases as the person with AD becomes more sensitive to the moods and feelings of the caregiver.

5) The person with AD may be confused, fatigued or in pain, but be unable to express what's wrong.

Coupling these tendencies with normal age-related "slowing down" is frustrating, as easy tasks become more difficult to perform and energy is decreased. A short temper should come as no surprise! Many older adults who value their independence may have trouble accepting help, even when they know they need it. With Alzheimer's Disease, the need to accept help is even greater, and resistance is exacerbated by a lack of understanding about disease-induced changes.

Catastrophic Reactions

The term "catastrophic reaction" refers to a behavior which is overreactive and which frequently occurs when the situation overwhelms the limited thinking capacity of the brain impaired person (Hall, Schleuter, & Colvin, 1993). Several examples or types of catastrophic reaction are (1) acting out; (2) catatonia; (3) wandering (See Caregiver Lesson Plan on Managing Wandering); (4) emotional projection; (5) sexually inappropriate behavior; and (6) resistive behavior (See Caregiver Lesson Plan on Resistive Behavior Associated with ADLs). There are several categories of triggers (personal, situational and environmental) which may elicit such behavior. The prudent caregiver can prevent them altogether in some cases, and reduce or diffuse the intensity of the episode in others. Since some catastrophic reactions are potentially dangerous to the person with dementia and his caregiver, it is vitally important for the caregiver to be aware of the stimuli that may trigger such responses and be alert to intervene.

Although hostile behavior may appear to happen for no reason, a closer inspection of the situation usually reveals one or more of the following triggers which may lead to physical and/or verbal abuse or other expressions of anger:

Personal Triggers
Inability to understand a request or question, or being bombarded with several questions
Inability to express oneself verbally
Inability to please the caregiver or to do a simple task
Inability to care for self
Fatigue
Medication
Hallucinations
Delusions
Fear
Embarrassment
Frustration
Physical discomfort (pain, fever, constipation)
Feeling lost, abandoned

Situational Triggers
Change from the routine; relocating
Introduction of new people
Caregiver moving too quickly or from behind
Crowds; confusion
Too much activity

Environmental Triggers
Falling barometric pressure
Change in lighting (dusk and dawn)
Increasing background noise (lawn mowers, pets, phone ringing)
Going outside into cold or inclement weather

The basis for developing appropriate interventions is to try to understand the feelings or emotions (fear, frustrations, etc.) that the family member is experiencing. Usually the caregiver has more control over the situational and environmental triggers than personal triggers. However, he may be able to prevent, reduce the number of, and reduce the intensity of aggressive episodes with interventions such as the following:

Personal Interventions

Pharmaceutical interventions are sometimes necessary, but should be used judiciously. The adverse side effects, (e.g., drowsiness, incontinence) may be worse than the aggression! Physical restraints ("geri" chairs) are not usually recommended because persons can actually harm themselves, and the effect of restraints may in fact aggravate the aggressive tendencies. Although aggressive behavior can be frustrating and problematic to caregivers, especially in communal settings, it has been suggested that it is a healthy expression of self and should be tolerated if it does not promote inappropriate conflict, danger, or loss of dignity. To minimize aggression, however, the caregiver can provide ways of releasing tension (e.g., safe place to pace, suitable physical activities as an alternative to aggression).

The caregiver should always keep in mind the possibility of physical danger and keep an exit route. Do not try to explain or argue. Remember the safety hierarchy or "protection priority":

1) Protect self from harm; you cannot be an effective caregiver if cornered or injured. If the person has a "hold" on you, ask him to pick up an object, thereby forcing him to release you.

2) Protect the care recipient from hurting themselves.

3) Protect the physical belongings. Don't risk safety to yourself or the person you care for by trying to protect documents, furniture, etc.

Situational Interventions

Approach the person slowly and calmly and within his field of vision, so he will not be startled. Position oneself out of the range of kicking or hitting.

Explain slowly and simply what you are going to do before doing it. Use simple one stage commands. Ask for help even if the person doesn't understand what you want, and involve him in self-care if possible. Limit choices to minimize confusion. If the activity is a distasteful one, use distraction by talking about something else, providing something else for them to do with their hands, or giving them a treat.

If the person with AD is resistant ("No!"), walk away and try again in a few minutes as if it were the first time. Do not argue.

Keep the environment simple and unchanged. Introduce new people one or two at a time. Avoid crowds, shopping malls, etc. Try not to ask too many questions, and reduce the number of decisions the person with AD has to make.

Build on strengths. Buy shoes that slip on and clothes with velcro closures to avoid the frustration of being unable to tie a shoe or button up a shirt.

Environmental Interventions

Maintain a peaceful simple environment to compensate for normal age-related sensory declines in hearing and seeing. Keep background noise (television, radio, conversation, etc.) at a normal consistent level. Use non-glare surfaces on floors, table tops, windows, etc.

Maintain "even" lighting throughout the areas of the house where the individual with dementia wanders. When going from outside to inside or vice versa, give the person's eyes time to adjust. Keep furnishings in the same place. Remove any object which could become a weapon.

Prevention

In trying to prevent aggressive episodes, the caregiver should be alert to the warning signs of aggression, such as:

1) A strained or confused look on face or glaring;
2) Clenched fists;
3) More restlessness or pacing than usual;
4) Trembling or crying;
5) Picking at clothes or self, ringing hands; and
6) Raising voice, shouting, or speaking faster.

The next step is to eliminate the trigger if it can be determined what the trigger is (e.g., noise? lights? too many people?) It is helpful to keep a diary of specific behaviors to help identify triggers. For example when, where, and how often did the specific behavior occur? Who was around? What happened before the behavior?

It also helps to remove the person from a potentially stressful situation into a quiet room with a familiar chair, favorite snack, or comforting object (stuffed toy, etc.) Another way the behavior can be diffused is by the caregiver's "non-reaction" to it -- speaking reassuringly, calling by name, staying calm.

AUDIO-VISUAL REINFORCEMENT:

"Before the Going Gets Rough" and "After the Going Gets Rough" produced and distributed by Good Samaritan Neurological Science Center, 1015 NW 22nd Avenue, Portland, OR 97210, (503) 229-7348. ($250 each or $475 for both; $25 Manual)

"Management of Difficult Behavior," a video segment from the Caregiver Kit, produced and distributed by the Alzheimer's Association, 919 N. Michigan Avenue, Suite 1000, Chicago, IL 60611-1676,(800) 272-3900.

"Alzheimer's Disease Pieces of the Puzzle: A Practical Approach to Problem Behaviors" produced and distributed by Biomedical Communications, The University of Arizona, Arizona Health Sciences Center, Tucson, Arizona 85724, (602) 626-7343.

EXPERIENTIAL LEARNING:

1) List three "problem" behaviors. Identify the trigger(s) and underlying feelings for each one. List three possible interventions, preventions, or diffusers.

examples:

Behavior	**Trigger**	**Underlying Feeling**	**Intervention**
Slapping or kicking	caregiver trying to undress the care recipient (situational trigger)	fear of assault	Explain calmly; have p.j.'s ready; give teddy bear to hold
Verbal abuse	being bombarded with requests (put on robe and bedroom shoes; wash face, brush teeth, etc.; and come to kitchen (personal trigger)	frustration because they can't remember what to do	Single stage request with clues (hold robe and hand each bedroom shoe; put toothpaste on brush, etc.)
Refusal to go outside	being approached with coat, hat, gloves (environmental trigger)	scared of what's "out there"	"You can put my coat on me, and I'll put your coat on you."

2) As a group, identify and discuss at least five frustrating changes an individual with dementia might experience. (Examples: impaired judgement, memory loss, difficulty in performing routine tasks, fatigue) Also review the feelings or emotions that may give rise to aggressive behavior. (Examples: anger, frustration, fear, confusion, embarrassment, feeling lost or abandoned)

3) Role play a situation where a potential episode of aggressive behavior was avoided. (Example: The care recipient approaches the caregiver with a knife in their hand. Caregiver calmly explains that the knife belongs in the kitchen.)

REFERENCES AND SUGGESTED READINGS:

Ballard, E. & Gwyther, L. (1990). Optimum care of the nursing home resident with Alzheimer's Disease. Durham, NC: Duke University Medical Center.

Coons, D., Metzelaar, L., Robinson, A., & Spencer, B. (1986). A better life. Columbus, OH: The Source for Nursing Home Literature.

French, C., Kline, N., & Levine, E. B. (1985). Understanding and caring for the person with Alzheimer's Disease. Atlanta, GA: Alzheimer's Association - Atlanta Chapter.

Hall, J., Schlueter, J. M., & Colvin, D. P. (1993, April). Assessment and treatment of behavior disturbance in dementia. Paper presented at the 14th Annual Meeting of the Southern Gerontological Society, Richmond, VA.

Noyes, L. E. (1991). Caregiving at a glance. Falls Church, VA: Family Respite Center.

Robinson, A., Spencer, B., & White, L. (1987). Understanding difficult behaviors. Ypsilanti, MI: Eastern Michigan University Geriatric Education Center.

Difficult Behaviors (S-04 CHID Search) is a literature survey (approximately 40 annotated entries) of recent literature in medical journals. Available at no cost from ADEAR Center, P. O. Box 8250, Silver Spring, MD 20907-8250 or call 1-800-438-4380.

Module 11: Managing Resistive Behavior Associated with ADLs

GOALS: To increase knowledge and understanding of the difficulty people with AD have with performing Activities of Daily Living (ADLs). To develop and apply appropriate coping strategies when assisting individuals perform routine but essential activities.

RATIONALE: Caregivers who observe and understand ADLs from the perspective of the person with AD, will be more effective in assisting with activities such as eating, bathing, dressing, toileting and managing incontinence.

EDUCATIONAL OBJECTIVES: At the end of this module, caregivers should be able to:

1) Define five activities of daily living and the difficulties they pose for the person with AD.
2) Explain several physical, cognitive and environmental causes for difficulties in performing ADLs.
3) Develop coping strategies to reduce catastrophic reactions.

MINI LECTURE:

Activities of Daily Living (ADLs) include: bathing, toileting, grooming, eating, and managing incontinence. People diagnosed with dementia may need little assistance with ADLs during the earlier stages of the disease. Later they will require increasing assistance with these essential activities as they lose the ability to perform ADLs. They may also forget to take care of these needs, or they may not remember having already completed an activity. For example, a person with Alzheimer's Disease may forget that he has eaten and protest that no one has fed him all day. In addition, they may be unable to evaluate the consequences of their own behavior.

When assisting persons with ADLs, allow them to function as independently as possible. Independent functioning helps people to feel in control and to maintain their sense of self-worth. Recognize that people want to take care of their own needs and may resist any assistance. During these situations a calm and gentle approach works best. Observe how the care recipient is trying to handle the activity and cue only as needed (see Caregiver Lesson Plan of Safety and Environmental Adaptations).

Bathing

There are a number of reasons why a person with dementia may resist bathing. They may be depressed and have no desire for personal hygiene. They may be embarrassed about being undressed, especially if the caregiver is a member of the opposite sex. They may even have an irrational fear of running water or mirrors. Does the person fear that the water will be too hot or cold, have too much force, or be too deep? Is the person afraid of being unable to regulate the water (leading to a fear of scalding), or to turn off the flow (leading to a fear of flooding the floor)?

Coping strategies. Follow the person's old routine to the extent possible (time & type of bathing). Prepare the bathroom ahead of time with soap-in-pocket washcloth, pre-measured shampoo, towels, robe or clothing, etc. For a tub bath, run the water ahead of time, test the temperature, and use only a few inches of water; remove all locks and electrical appliances from the area. Tomato juice in the water can help with persistent body odor. Use a plastic pillow for the person to lay back on. Use a hand held shower nozzle, if suitable.

Cue the person during each step of the bath. Make sure the person washes the genital area, especially if incontinence is a problem. A spray bottle with warm soapy water may be helpful, but be sure the area is rinsed completely. Background music (from another room) can help to create a calm soothing atmosphere. The lock should be removed from the bathroom door. Giving the care recipient something to occupy her hands will serve as a distraction during disrobing, bathing and dressing. Seat the person on the commode to urinate while disrobing. Stand at the side of the person to avoid being kicked. Avoid bath oils and use safety devices such as hand-rails, tub mats and tub seats.

Keep the bathroom warm and use a non-skid bath mat or carpet. Never leave the person alone. After bathing, see that the person is completely dry, check for skin rashes, bed sores, etc., and use baby powder or cornstarch. Consider sponge baths as an alternative to full baths.

Toileting

Persons with dementia may have lost the ability to recognize and respond to signals which alert them for the need to use the bathroom. They may forget where the bathroom is or forget what to do when they get there. Assisting with toileting activities may feel embarrassing for both you and your loved one. These feelings are normal and will subside as you become accustomed to the task.

Remain calm and try to be reassuring while dealing with these duties that feel unpleasant to both of you.

Coping Strategies. Post a colorful sign on the bathroom door, or paint it a contrasting color so it can be identified more easily. Set up a regular toileting schedule (e.g., once each hour). Watch for signals (e.g., restlessness). Respect the person's need for privacy, even though they may need assistance adjusting clothes or finding the correct position by being talked through each step. It may be helpful when seating a person on the commode to use a clothes pin to secure the dress, shirt or nightgown to the back of the collar.

Incontinence

Incontinence of bowel and/or bladder (and subsequent bed-wetting) is common among persons with AD in the latter stages (see Caregiver Lesson Plan on Maintaining Continence). Toileting accidents can often be managed during earlier stages by modifying the routine (e.g., toileting schedule), clothing (e.g., velcro closures), or environment (e.g., well-marked bathroom door). Eventually, however, the caregiver may have to accept incontinence as a way of life.

There are any number of factors which may contribute to incontinence. Medical problems (urinary tract infection, constipation, prostate problems, diabetes, stroke, Parkinson's Disease, inability to ambulate fast enough to get to the bathroom in time, etc.) may be to blame. It's also possible that medications (tranquilizers, for example) are causing the bladder muscle to be too relaxed. Diuretics and beverages with caffeine may also contribute to incontinence.

It's possible that the family member can't remember where the bathroom is, or it's too far away to reach in time. Is the person concerned about falling or tripping over something on the way to the bathroom, or is it too dark to find the bathroom? Is the clothing too cumbersome (zippers, buttons, tight underwear) to manipulate?

Coping Strategies. DO NOT BLAME OR SCOLD THE PERSON! The situation is already embarrassing enough. Restrict fluid intake two hours before bedtime. Use a high fiber diet and avoid using laxatives. Dress the person in easy to manage clothing, such as sweat pants with an elastic waist, and eliminate underwear if necessary. Use a night light and/or place a commode or urinal near the bed at night. Use disposable briefs or adult pads as needed. Cover the bed and chairs for easy clean-up of accidents. Be sure to clean the person properly using a wash cloth or disposable wipes to help avoid skin irritation.

When the care recipient begins to loose bladder or bowel control, a physician should be consulted. The problem may be helped by changing the diet. Make sure the person is adequately hydrated (1 1/2 quarts = 6 cups liquid daily).

Dressing and Grooming

For the person with dementia, the simple act of putting on clothing can be frustrating. For example, does the person have problems with balance or the fine motor skills to close zippers and fasten buttons? Does the person recognize his/her own clothes? Is the person embarrassed by lack of privacy or a cold room or the need to get dressed quickly?

Coping Strategies. Avoid discussions and choices by laying clothes out in the order in which they are put on (e.g., under-garments, socks, trousers, shirt). Remove clothing that is not worn regularly from closets and drawers. Simple garments with simple fasteners allow more independence and make dressing a less difficult task. Clothing should fit comfortably; non-skid shoes (e.g., tennis shoes) may reduce accidents such as falling.

Encourage persons to dress themselves and follow their old habits (e.g., makeup, hair style, etc.). Independence and a clean tidy appearance foster self-esteem. Compliments and praise will also help people to feel better about themselves and will help both caregiver and care recipient to start the day on a "good foot." Be flexible and try not to rush or hurry the grooming process.

Eating

As with toileting/incontinence, there may be any number of factors contributing to difficulty with eating. Medical problems (dry mouth, Parkinson's Disease, gum disease, ill fitting dentures, chronic or acute illnesses, constipation, depression, or the side effects of medications) may be the cause. In addition, the person may experience a poor sense of taste or smell (both of which are incentives to the normal desire to eat). Confused persons may forget that they have already eaten or how to use utensils. In advanced stages, the muscles in the jaw and throat no longer work properly. Environmentally, the person may be distracted from eating by agitation due to relocation, poor lighting, too many distractions, too many choices of food, too many items on the table, too many people, etc.

Coping Strategies. Have appropriate medical, dental, and visual work-ups to eliminate problems that may be contributing to loss of appetite. Consider serving the person alone before the rest of the family eats to ensure adequate nutrition, but have the person at the table just for social interaction. Limit food choices and utensils by serving only one food at a time; finger foods, pre-cut or pureed foods are excellent alternatives. Serve the person's favorite foods. Check the food's temperature and encourage the person to "eat slowly, chewing each bite." When needed, use simple, one-step instructions, repeating them when necessary. Serving food in bowels and undecorated dishes may work best. Use a plate with a rim and suction cup bottom or non-skid place mats in contrasting colors. Use non-breakable plastic colorful mugs with large handles. Try cups with lids and a bendable straw. Do not use styrofoam cups; not only do they tip over easily, but persons may try to eat them.

Avoid dangerous accidents! Try not to keep anything around that may look like food (such as wax fruit, candies made from glass, dog biscuits, etc.), because they may be mistaken for food and eaten. Make sure food is not too hot. Encourage the person to eat by using a calm, soothing voice, but do not force them to eat. Avoid sticky foods (peanut butter, bananas) or hard to swallow foods (popcorn, nuts, raw vegetables). If choking with liquids is a problem, use thicker liquids (milkshakes vs. milk). If choking with solid foods is a problem, try soft cooked foods like scrambled eggs, jello, cottage cheese, frozen yogurt, mashed potatoes, or chopped chicken. To ensure adequate nutrition, use supplements (e.g., Ensure or Sustacel). Back-ground music can sometimes help calm the person while he eats.

In conclusion, caring for a person with AD is a difficult and demanding job, and one that people are often unprepared to handle. The first step in coping with the stress of caregiving is understanding the disease and accepting the situation. Knowledge of the disease will assist caregivers in understanding the needs of the care recipient and better prepare them to handle particular problems that are associated with the disease.

No matter which ADL you are assisting with, always use a warm loving voice in giving single stage directions. Express appreciation for positive behavior and point out successes. Don't rush or criticize the person; he is doing the best job possible. Persons with AD may have forgotten how to perform tasks, but they remember love. Hug and show affection to your loved one.

AUDIO-VISUAL REINFORCEMENTS:

"Managing with Alzheimer's Disease" produced and distributed by Good Samaritan Hospital and Medical Center, 1015 NW 22nd Ave., Portland, OR 97210, (503) 229-8038.

"Meeting Daily Challenges" (a 20 minute video in the Caregiver Kit) produced and distributed by the Alzheimer's Association, 919 N. Michigan Avenue, Suite 1000, Chicago, IL 60611-1676, (800) 272-3900.

"Alzheimer's Disease Pieces of the Puzzle: A Practical Approach to Activities of Daily Living" produced and distributed by Biomedical Communications, The University of Arizona, Arizona Health Sciences Center, Tucson, AZ 85724, (602) 626-7343.

EXPERIENTIAL LEARNING:

1) At the end of this module are three handouts depicting common behavioral problems occurring with mild, moderate, and severe dementia (Hall, Schleuter, & Colvin, 1993). Using a few examples from each handout page, describe the problem and ask participants to suggest ways of dealing with the difficulty. After suggestions have been offered, review the behavioral interventions listed.

REFERENCES AND SUGGESTED READINGS:

Crichton, J. (1987). Age care sourcebook: A resource guide for the aging and their families. New York: Simon and Schuster.

Edinberg, M. (1987). Talking with your aging parent. Boston: Shambhala Publications, Inc.

Hall, J., Schlueter, J. M., & Colvin, D. P. (1993, April). Assessment and treatment of behavior disturbance in dementia. Paper presented at the 14th Annual Meeting of the Southern Gerontological Society, Richmond, VA.

Halpern, J. (1987). Helping your aging parent: A practical guide for adult children. New York: McGraw-Hill.

Hooyman, N., & Lustbader, W. (1986). Taking care: Supporting older people and their families. New York: McMillan, Inc.

Noyes, L. E. (1991). Caregiving at a glance. Falls Church, VA: Family Respite Center.

Robinson, A., Spencer, B., & White, L. (1989). Understanding difficult behaviors. Ypsilanti, MI: Eastern Michigan University GEC.

Samantha Walker is gratefully acknowledged as a contributor to this module.

Managing Behavior Problems in Dementia

MILD DEMENTIA

Common Problems	Behavioral Interventions
Impaired selective attention (ability to attend to a specific stimulus in a complex environment)	Minimize potential distractors; simplify environment (e.g., remove extraneous clutter); approach tasks one at a time; avoid hectic surroundings (e.g., group rooms with multiple simultaneous conversations)
Learning and recent memory deficits	Encourage use of memory aids and reminders (e.g., diaries, journals, pocket calendars, "post-it" notes, address books)
Misplacing/losing personal possessions	Establish a central location for all personal possessions (e.g., large wicker basket or cigar box for wallet, keys, purse) and place in high traffic areas
Receptive/expressive communication deficits (language comprehension and communication)	Speak slowly, distinctly, and softly; avoid open-ended questions (e.g., "What would you like to do today?"); avoid mixed communications; express a single thought per exchange; emphasize nonverbal cues (e.g., smiling holding hands); have individual repeat message
Dysnomia (word-finding difficulties)	Focus on content of message rather than specific words; avoid over-correction of word error
Denial of deficits or attempts to "cover up" (confabulation)	Use respect in response to individual's denial as a coping skill, yet ensure the individual's safety

Hall, J., Schlueter, J. M., & Colvin, D. P. (1993, April). Assessment and treatment of behavior disturbance in dementia. Paper presented at the 14th Annual Meeting of the Southern Gerontological Society, Richmond, VA. (Used with Permission)

MODERATE DEMENTIA

Common Problems	Behavioral Interventions
Confusion and disorientation	Utilize "orientation center"; minimize distractions (e.g., clutter), use repetition, focus on season rather than day or month
Difficulties with bathing, grooming	Use simple "one-step" directions, tolerate variations in personal habits, modify bathroom (install rails, bathing chair, hand operated shower head), use single-use dispensers for soap and shampoo; employ humor
Changes in sexual behavior	Identify and change settings (as opposed to behaviors) which may be inappropriate; recognize impairments and limitations; initiate intimate and affectionate exchanges
Perseveration	Use distraction; engage in tasks which are repetitive in nature (e.g., drying dishes, sanding wood)
Sleep disturbances	Encourage regular exercise and sleep hygiene (i.e., discourage daytime naps); prevent boredom; consider physician consultation for medications
Angry outbursts and agitation	Identify the triggers and avoid/eliminate them; respond in a calm, reassuring voice; smile and try touch if this does not cause further upset; use distractors (e.g., focus on deep breathing exercises); leave the room if needed

Hall, J., Schlueter, J. M., & Colvin, D. P. (1993, April). Assessment and treatment of behavior disturbance in dementia. Paper presented at the 14th Annual Meeting of the Southern Gerontological Society, Richmond, VA. (Used with Permission)

SEVERE DEMENTIA

Common Problems	Behavioral Interventions
Decreased recognition of family and familiar places	Use links from the past (e.g., photo albums, portraits, other memorabilia); use reassurance and repetition; avoid over-correction of naming errors
Problems in dressing	Initially, offer help with choosing clothes, then with actual mechanics of dressing; use "one step" directions; modify wardrobe (e.g., sweatshirts which can be worn inside-out and/or backwards, tube socks instead of dress socks, slip-on shoes instead of shoes with laces, pants with elastic waist bands instead of belts, one-piece coveralls), avoid rushing
Eating problems	Avoid rushing mealtimes, serve foods easily broken or eaten with one utensil; use "finger foods"; provide the individual with one food item at a time; instruct when to chew and swallow
Incontinence	Consult physician to rule out complicating factors (e.g., urinary tract infection); use routine toileting; restrict fluid intake after evening meal; use special clothing and incontinence pads; increase environmental cues (e.g., arrows on floor and sign saying "toilet")
Falls	Eliminate throw rugs or other safety hazards; install night lights; use walker or cane; supervise ambulation; have a plan to assist the fallen person; use monitors

Hall, J., Schlueter, J. M., & Colvin, D. P. (1993, April). Assessment and treatment of behavior disturbance in dementia. Paper presented at the 14th Annual Meeting of the Southern Gerontological Society, Richmond, VA. (Used with Permission)

Module 12: Managing Wandering

GOAL: To increase knowledge and understanding of wandering behaviors in people with Alzheimer's Disease and to learn skills to prevent and/or manage wandering behaviors.

RATIONALE: Caregivers who understand wandering behaviors, and learn skills to deal with them, will experience increased feelings of mastery in their daily work.

EDUCATIONAL OBJECTIVES: At the end of this module, caregivers should be able to:

1) State the symptoms that contribute to wandering behaviors.
2) Describe types of wandering behavior.
3) List three interventions that will help deter wandering.
4) List five safety precautions to prevent wandering.

MINI-LECTURE:

People with AD may or may not wander. Some retain enough insight to know that they will get lost and tend to stay in a very familiar environment to feel safe. Caregivers may have trouble coaxing these people to go new places or do something different.

Many other people may have the following symptoms that can lead easily to wandering:

1) Trouble recognizing familiar landmarks (inside the building or out);
2) Difficulty maintaining a sense of direction;
3) Trouble recognizing objects from their background;
4) Difficulty understanding time/distance issues (wishing to return to a home that is no longer there or in another city); and
5) Memory loss.

Types of Wandering

There are many types of wandering. Some people with dementia go through a hyper motor period which lasts about nine months. During this time the person cannot stay still and may wander away by accident. Others may loose interest in their present environment and wander because there is nothing to keep their interest. Some Alzheimer's persons may retain their abilities to be clever and even develop Houdini like skills at getting away despite the caregiver's best attempts.

Caregivers can become very frustrated with people who wander. It may be difficult to remember that the behavior flows from a diseased brain, when it seems that the person is willfully trying the patience of the caregiver.

Interventions that Deter Wandering

It is important to determine which type of wandering a person is displaying in order to choose a successful intervention. Sometimes your own creativity can help you figure out ways that work for a particular person. Rarely are physical restraints necessary to prevent wandering. Sometimes the use of restraints leads to physical injury. Medications are rarely effective against wandering, unless restlessness or agitation are the precipitants of the behavior.

Environmental Interventions

1) Provide a safe place for wandering
2) Hang bells on door knobs to alert you to opening of taboo doors
3) Post signs that say STOP! or DO NOT ENTER!
4) Appoint someone to monitor exits when wandering is likely.

Communication Interventions

1) Verbal instructions to stay put are unreliable. People with memory loss, and possible anxiety, are not going to be able to comply with your requests to stay in one place.
2) If someone tries to leave their safety zone, ask him to help you with something
3) Do not say "NO!" or "Stay here!" or "You can't leave!" Instead ask the person for help or redirect him to a different place. Call him by name and then change the subject. "Would you please come over here, I need your help," is an effective distraction.

Behavioral Interventions

1) Try "sock therapy." A person who normally wears shoes outside may not leave if he is in his stocking feet. Don't put the person's shoes on until it is safe for him to leave the building.
2) Find appropriate activities for people that hold their interest so they will not be bored and wander away.
3) If someone is leaving rapidly, do not pull on his arm to try and detain him. Instead walk in step with him for a while and then redirect him by asking for help or offering to fix a beverage or snack.
4) Take the person for supervised walks.
5) Keep an updated picture of the person where you can find it in a hurry.
6) Have an emergency search plan in place.
7) Enroll the person in the Alzheimer's Association's "SAFE RETURN" program which will provide the person with an ID bracelet and access to a nationwide missing person program. For the number of your local Alzheimer's Chapter call the National Office at 1-800-272-3900.

AUDIO-VISUAL REINFORCEMENTS:

"Managing Difficult Behaviors: Wandering and Inappropriate Sexual Behaviors" (in the series Managing and Understanding Behavior: Problems in Alzheimer's Disease and Related Disorders) produced by the Alzheimer's Disease Center, University of Washington. Distributed by the Alzheimer's Disease Education and Referral Center, P.O. Box 8250, Silver Spring, MD 20907-8252. (800) 438-4380.

EXPERIENTIAL LEARNING:

1) Distribute the handout at the end of this module. Discuss each type of wandering and the suggested interventions. Have the group suggest others.

2) Lead the group in a role play scenario which demonstrates each type of wandering. One volunteer should assume the role of the Wanderer, and another should intervene.

3) Ask caregivers to share stories and feelings about times they have been lost. Begin the discussion with an example from your own experience.

REFERENCES AND SUGGESTED READINGS:

Hall, G. R. (1984). Standard care plan for the patient with a dementing illness. Iowa City, IA: University of Iowa.

Noyes, L. E. (1991). Caregiving at a glance. Falls Church, VA: Family Respite Center.

Lin E. Noyes is gratefully acknowledged as the major contributor to this module.

Types of Wandering

1) Recreational Wandering: This type of wandering occurs if the person was active before or was used to taking walks. During recreational wandering the person is usually calm, unless stopped. Wandering recurs regularly, seeming to fill a need for exercise. **Schedule walks as part of the daily routine.**

2) Tactile Wandering: In this type of wandering, persons appear to be blind. They calmly feel their way down hallways, exploring the environment with their hands as they go. The frequently just "get lost" by accident. **Direct the person away from unsafe places. The person should be allowed her freedom and given opportunities to explore the surroundings safely.**

3) Environmentally-Cued Wandering: Although apparently calm, the person may elope on a regular basis. There is an unmistakable tendency to respond to cues in the environment. For example, after seeing a chair, the person may sit. Upon seeing a door, the person will go through it. **Disguise door-ways or put "stop" cues in front of exits. Consider placing a chair in front of exits to encourage sitting, rather than leaving. Get the person involved in other activities to distract attention away from the environmental cues.**

4) Reminiscent/Fantasy Wandering: The person may be calm but want to leave based on a delusion or fantasy from the past. He may say he is leaving to go to work (even though he has retired), to go see his parents (although they are deceased), or to go home (though he is already at home). **Redirect the activity. Acknowledge the "need" to go and then, ask for help with something that will keep the person otherwise occupied. Caregivers may want to gently correct the misconception, and then divert the person's attention to something else.**

5) Agitated/Purposeful Wandering: The person is preoccupied with leaving and may be upset, fearful, and agitated. Aggressive or threatening behavior may be involved. **Prevent the stressor or diffuse the stress reaction if possible. Assure the safety and security of yourself and the wanderer. Don't confront or contradict the person. It's best to simply change the subject.**

6) Internally-Cued Wandering: The person may pace because he feels physically uncomfortable. **Learn the person's schedule for hunger, defecation, and urination to avoid discomfort.**

(Adapted from G. R. Hall, Standard Care Plan for the Patient with a Dementing Illness. Iowa City, IA: University of Iowa.)

Module 13: Communicating with the Person Who Has Alzheimer's Disease

GOAL: To increase knowledge and understanding of special communication needs of people with dementing illnesses, and to learn skills that can facilitate communication.

RATIONALE: Family members who understand how dementing illnesses can change communication and who learn techniques to counteract these changes, will become more appropriate caregivers.

EDUCATIONAL OBJECTIVES: At the end of this module, caregivers should be able to:

1) Define aphasia.
2) Describe at least three difficulties with language a person with Alzheimer's may have.
3) Demonstrate three techniques that will enhance communication.

MINI-LECTURE:

The ability to talk, see, hear, and communicate with other people is a function we take for granted. Communication is an integral part of life. Relating to and interacting with other people, pets, and our environment is the essence of living. Not only is communication essential to obtaining information about others, ourselves, and the environment, but it contributes to our quality of life.

Interpersonal relationships are important throughout life, and they are developed and maintained via communication, much of which comes through the senses. In advanced age, the need to communicate is especially vital to counteract physical, emotional, and social losses, but sensory impairment makes communication more difficult. When a person experiences cognitive (intellectual) impairments, as with AD or a similar dementia, he is in a very vulnerable position.

After memory loss, diminishing communication skills are the most frequent problem associated with dementing illnesses. Like memory loss, early language problems may be very subtle -- a slip of the tongue, one word used where another one should be, etc. As the disease progresses, problems become worse until people talk incoherently or stop talking altogether. The inability to express thoughts in language or to understand the spoken word is called aphasia. Typical problems include:

1) Not recognizing a word or phrase, almost as if the word were in a foreign language;
2) Not being able to think of the names of things (anomia);
3) "Perseveration" or repeating the same word or phrase over and over;
4) Misnaming people or objects, but getting close (using "mom" for "sister"); and
5) Losing all meaningful language except for outbursts.

It is important to remember that a person's ability to understand what you are saying long outlasts his ability to speak coherently. Despite the communication problems, adults are still adults and communication should always be on an adult level.

Communication Techniques

Make sure the person knows you want to talk before you begin and try the following methods.

1) Make eye contact.
2) Use gentle touch to get his attention.
3) Call the person by name.
4) Deliver your messages using short, simple words.
5) Keep communication on an adult-to-adult level. Avoid baby talk or demeaning expressions.
6) Smile, shake the person's hand so that he knows you are approaching him as an adult.
7) Speak slowly.
8) Give only one message at a time.
9) Limit choices. If its time for lunch, don't ask the person if he would like to eat. Instead, just say, "Its time to eat, come with me."
10) Reduce background noise if possible. Although you can screen out other conversations, the person with a dementing illness probably can't.
11) Although it often seems like a waste of time, it's important to keep on talking even when you are sure you aren't getting through. Explain what you're doing, update the person on familiar events, and use your gift of gab in an attempt to stay in touch with your loved one.

Since Alzheimer's Disease is typically a disorder experienced by older rather than younger adults, the changes in the brain are superimposed on normal age-related sensory losses. (See Caregiver Lesson Plan on Safety and Environmental Adaptations and Chapter on How Adults Learn). Some of these normal changes are as follows:

Vision: Colors are more difficult to differentiate, especially pastels. More light is required to see, especially if reading. It takes longer for the eye to adapt to changes in lighting, as in going from inside to outside or vice versa.

Hearing: There is a decline in auditory acuity, especially at high frequencies. The range of sounds that can be heard becomes narrower. Hearing loss is greater for consonants than vowels. ("Cat" sounds like "sat").

Taste and Smell: Both of these senses decline and can be safety risks. For example, one might eat spoiled food or not smell smoke.

Touch: This sense is the last to decline, which is fortunate, because touching (e.g., handshakes or hugs) can be effective forms of communication.

The combined impacts of these senses can lead to self-imposed social isolation. Persons may not want to "eat out" because they fear they might embarrass themselves at the dinner table. In addition, they cannot discriminate the table conversation from the background noise, or pick up on nonverbal cues in dim lighting. Even worse, persons may become depressed or paranoid because they can't accurately hear what's being said.

The first recommended video provides scenarios in which you can see and hear what an older person with normal age-related sensory losses, but without Alzheimer's Disease, is experiencing. One can only imagine what it's like to add the deficits of AD (memory loss, aphasia, reduced mobility) to normal losses.

AUDIO-VISUAL REINFORCEMENT:

"Age-Related Sensory Losses: An Empathic Approach" produced and distributed by the Gerontology Institute, University of Michigan, Ann Arbor, MI.

"Alzheimer's Disease Pieces of the Puzzle: A Practical Approach to Communication" produced and distributed by Biomedical Communications, The University of Arizona, Arizona Health Sciences Center, Tucson, Arizona 85724, (602) 626-7343.

EXPERIENTIAL LEARNING:

1) Ask group members to recount experiences when they have been unable to find a word -- something right on the tip of the tongue that just wouldn't come out.

2) Demonstrate the difference between talking down to someone and speaking on an adult to adult level.

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Lin E. Noyes is gratefully acknowledged as the major contributor to this module.

Module 14: The Caregiver's Spiritual Resources

GOAL: To help caregivers recognize the spiritual strengths that are within every human being, and to utilize religious resources, if appropriate, in the caregiving process.

RATIONALE: Caregivers who are aware of their own spiritual and/or religious resources and strengths can draw upon them in dealing with their own feelings, and providing appropriate care for their loved ones.

EDUCATIONAL OBJECTIVES: At the end of this module, caregivers should be able to:

1) Distinguish between spirituality and religiosity;
2) List three examples of spirituality;
3) List three examples of religiosity;
4) Express how the person with a diagnosis of Alzheimer's Disease feels in the early stages, when he is aware of what is happening;
5) Identify three ways in which the congregation can minister to the family with Alzheimer's Disease

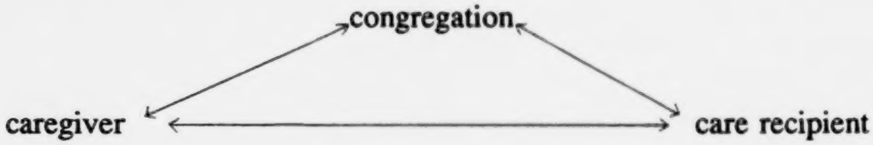
MINI-LECTURE:

The dictionary defines "spirituality" (in part) as "incorporeal or immaterial nature; spiritual nature as shown in thought, life, etc." The spiritual dimension of an individual is basic to life and identity. Spiritual beliefs and convictions give life meaning. The integration of a person's physical, emotional and spiritual components contributes to a sense of well-being (American Association of Retired Persons, 1989).

In essence, every person is spiritual, i.e., has a spirit or "incorporeal nature" that is characterized by their thoughts and consequently their actions. Any person who is ethical and upright (e.g., a good citizen), performs good deeds (e.g., contributes to charity), obeys the "Golden Rule" (e.g., treats others with respect), practices environmentally-sound behavior (e.g., recycling), or develops global awareness (e.g., avoids aerosols to protect the ozone layer) is acting responsibly in recognition of his own spiritual being and that of others. People can do all kinds of good things based on their spiritual nature. They can, in fact, be atheists (who do not believe in God) or agnostics (who subscribe to no specific belief system), and still be good people who do good things in response to their own spiritual nature. Again, everyone is endowed with a spiritual nature, whether on not they choose to act on it.

Religiosity, however, is not an inborn trait. An individual must seek a belief system and a personal theology to be religious. Religiosity refers to devoutness and personal piety. It is a subjective measure of one's religious involvement (Taylor & Chatters, 1988). It may come as a surprise that religiosity does not have to be related to a sect, denomination, or regular corporate worship in a church, synagogue, mosque or temple. Personal piety or devoutness can be practiced in isolation (e.g., prayer, meditation, scripture reading, faith/belief development). For the most part, however, individuals who seek a personal theology do so under the auspices of a faith tradition, primarily Protestant, Catholic or Jewish in this country. For purposes of discussion, we will focus on churches and synagogues.

Although this module deals with the spiritual and/or religious resources of the caregiver, at least two other perspectives are relevant: (1) the spiritual and/or religious resources of the person with Alzheimer's Disease in the early and middle stages or for as long as he has any memory of God; and (2) the role of the congregation, both clergy and laity, in supporting the caregiver (both emotionally and instrumentally) throughout the stages of the disease. This relationship might be characterized as follows:



So much has been written about the "burdens" and "hassles" of the caregiver, that we sometimes lost sight of the person with Alzheimer's. A person who has been diagnosed with Alzheimer's Disease and is aware of the prognosis has a terrible burden to bear: the knowledge of (1) progressive loss of memory and mental abilities; and (2) increased dependency on others and ultimately death. Persons with Alzheimer's Disease from Jewish, Protestant and Catholic traditions can draw on passages from the Old Testament, especially these selected verses [Psalms 71:9, 12, 17-19a (NIV)]

Do not cast me off in the time of old age;
        forsake me not when my strength is spent.
O God, be not far from me;
        O my God, make haste to help me!

O God, from my youth thou hast taught me,
 and I still proclaim thy wondrous deeds.
So even to old age and gray hairs,
 O God, do not forsake me,
till I proclaim thy might
 to all the generations to come.
Thy power and thy Righteousness, O God,
 reach the high heavens.

A prayer of comfort to the person with Alzheimer's Disease might be:

> "Lord, I feel confused and afraid. What is happening to me? I ask you to guide my doctors, family, and pastor so that they may help me and care for me in my times of need. Continue to provide me with assurance of your love and care. I put my trust in you. Amen. ("Forgetfulness? Confusions? Fear?", University of Pittsburgh Medical Center, 1990).

As the reality of the diagnosis sets in, family members may feel overwhelmed at the hopelessness of the disease. They may become depressed and go through the stages of grief (see Caregiver Lesson Plan on The Grieving Process). They see a loved one slowly slipping away and are powerless to stop the decline. They lack knowledge about the disease process, its management, and available resources to help. Not surprisingly, many fear an unknown future. They may ask "Why?," the title of a poem by the caregiver Maude Newton, as she did in the closing lines of her poem:

"Why, God - if you are my God, why?" (Gruetzner, 1988).

Similarly a poem by Sally Woodard ("Letting Go") lends itself to the experience of "daily dying" in a relationship which parallels that of a caregiver of a person with dementia. She speaks of the difficulty of letting go from ..."habits, association, memories.....places, things, people.....dreams and rememberances." But she concludes on a note of optimism:

"Letting go
Is painful
But necessary
For
 Growth to continue
 Newness to emerge
 Freedom to become." (Woodard, 1995)

One person who found spiritual enrichment and balance through journaling, shared the following prayer from her journal. She incorporated elements of praise, thanksgiving, confession, and intercession for others throughout the world before rendering personal petitions for her family.

> "Creator of the universe, we offer you our praise and adoration for sharing your handiwork with humankind. We thank you for the gift of life and being a part of your created order. We confess we have often failed in our stewardship of natural resources and have also fallen short in recognizing and loving our neighbors throughout the world even as we love ourselves. We ask that you make your presence known throughout all the world, especially in those parts of the world where injustice and oppression prevail. I ask for your consolation as I care for my spouse and for the needs of my family members as we deal with multiple losses and the pain of watching a loved one die by degrees. You know our specific needs even before we utter them. Grant us your grace and remain faithful to us, your servants. In Your Holy Name, Amen."

As the disease progresses, the environment (even home) can become a scary place, and outings -- even to church -- may become problematic. It's quite likely that both caregiver and care recipient are members of the same congregation. Both will still be integral to their community of faith even after regular attendance for one or both of them becomes difficult, if not impossible. Some familiar rituals of congregate worship which have provided sustenance will become lost to them. Some radio and television programs may help to alleviate that loss through familiar hymns, preaching, and prayers. One vital loss is that of participating in the sacraments. Both caregiver and care recipient should be able to have the rites administered at home by the ecclesiastically sanctioned authority (e.g., pastor, priest, rabbi, or ordained laity). Even after the care recipient has forgotten the reason for the sacrament, he may be comforted by the familiar act.

Both caregiver and care recipient can be undergirded by a small faith enrichment group, invited into the home by the caregiver, and facilitated by either clergy or laity. Religious study opens the door for individuals to share their own life experiences which led to their faith development. Especially helpful is reminiscence. The person with AD may be able to recall pivotal experiences in his life. The care recipient may not understand much of what is happening, and may indeed be wandering around while everyone else is sitting. He will still feel secure with familiar, safe people even though he no longer remembers who they are.

The caregiver who develops his religiosity, as well as his spirituality, will have more tools to draw on. Engaging in the daily disciplines of prayer, meditation, scripture reading, and other acts of personal piety can be relaxing and uplifting. Intercessory prayer is another way in which both the caregiver and friends in the faith community can support one another. Prayer can be lifted on behalf of all those who take care of the person with AD, whether family members or health care professionals. The caregiver can pray for both himself and the care recipient.

There are particular passages from the sacred texts that may be meaningful, depending on one's faith tradition. For example, Psalms 46:1 reads:

"God is our refuge and strength,
a very present help in trouble."

Isaiah 43:1b-2 offers these words of encouragement:

"Do not fear, for I have redeemed you;
I have called you by name, you are mine.

When you pass through the waters,
I will be with you;
And through the waters,
they shall not overwhelm you;
When you walk through the fire,
you shall not be burned,
and the flame
shall not consume you."

Other Psalms of comfort are Chapters 34, 91, 107, and 118. In the New Testament, Ephesians 3:16-21 and Romans 8:35-39 offer encouragement for caregivers, even for those who feel guilty about their negative feelings (Sistler, 1993).

What is the church's role in this interaction? Second Corinthians 1:3-4 holds the key:

"Blessed be the God and Father of our Lord Jesus Christ,
the Father of mercies and the God of all consolation,
who consoles us in all our affliction,
so that we may be able to console those who are in any affliction
with the consolation with which we ourselves are consoled by God."

Families definitely need both emotional consolation and instrumental support (e.g., money, transportation, respite, grocery shopping, etc.) and empathy. Fellow Christians and Jews can affirm the importance of a strong faith and trust in God's sovereignty. Those who can trust God to help them through seem to cope better than those who try to carry the whole burden on their own shoulders (Sistler, 1993).

African American churches have historically responded to a need such as Alzheimer's Disease with extended kin roles (Walls, 1992). The church complements and interacts with the family. Furthermore, black churches can play a pivotal role by linking families with the formal services delivery system. What are the services they need? Caregivers have reported the need for affordable respite services (i.e., relieving the caregiver of his duties for a time); counseling to help resolve family conflicts; and information regarding Alzheimer's Disease and community resources (Segall & Wykle, 1988-89). In addition, they need more information about the disease; strategies for management of the disease and care of the person; and a support network (Sistler, 1993).

Studies have shown that black caregivers of all ages use religious faith as a way of coping with the stresses of caregiving. When asked for one special way of caring for a confused relative, 65% of caregivers reported that prayer, faith in God, and religion were their primary ways of coping (Segall & Wykle, 1988-89). The same study revealed that no caregivers reported being overwhelmed or unable to care for their loved ones. This is consistent with the finding of a dominant theme in the same study -- accommodating oneself to the situation. This fact may partially explain the underutilization of institutions for the elderly by blacks as compared to whites (Watson, 1987).

Both historically and contemporaneously, religion and religious institutions have played a crucial role in the lives of Black Americans (Taylor & Chatters, 1988). Black churches have been responsive to the needs of a community whose access to traditional social institutions has been restricted. The unique niche filled by the church may derive in part from the fact that black churches are completely financed, built and controlled by blacks (Frazier, 1974). Indeed, black churches are second only to the family as an important social institution. Blacks tend to display higher levels of religious involvement than whites (Greely, 1979; Nelsen, Yokley, & Nelson, 1971; Sasaki, 1979). In the black community few social institutions other than the church endure over a major portion of the life course (Taylor & Chatters, 1988). This is consistent with the concept of a support convoy (Kahn, 1979). A support convoy involves support networks which endure throughout the life course and vary according to life events, e.g., marriage, christening, divorce, relocation, death, and last rites (Wimberly, 1979).

White (Anglo) churches have not been perceived to be as involved in the delivery of social services as black ones. In reality, variables such as a high percentage of elderly, denomination, church size, socioeconomic status of members, and numbers of homebound may be better predictors of relationships with social service agencies than whether the church is predominantly Black or Anglo (Wilson & Netting, 1988).

Pilot projects in Interfaith Volunteer Caregiving funded by the Robert Wood Johnson Foundation over the last several years have demonstrated that churches and synagogues, and their congregations, both white and black, can work collectively to form consortia for service delivery and caregiver support. The time has come for faith traditions to link with social service networks. Together they can better meet the needs of congregants and others within the community to provide emotional, educational and respite support for persons with Alzheimer's Disease and their family caregivers.

AUDIO-VISUAL REINFORCEMENT:

"Even These May Forget." (A Pastoral Care Challenge: Training Program for Clergy) produced and distributed by University of Pittsburgh Medical Center, Alzheimer's Disease Research Center, Iroquois Building, 3600 Forbes Ave., Pittsburgh, PA 15213.

EXPERIENTIAL LEARNING:

1) Explain at least three ways in which congregations might support a family with Alzheimer's Disease during the person's early stages, middle stages, and later stages.

2) List six passages from the scriptures that could be meaningful to the caregiver as a coping mechanism and explain why.

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Module 15: Compassionate Caregiving

GOAL: To increase knowledge and understanding of the psychological comfort needs of people with dementia in all aspects of daily living. To develop and apply suitable strategies which will promote psychosocial comfort and self esteem for the care recipient.

RATIONALE: Persons with dementia have the same basic psychological needs as any other adult. Caregivers who understand this will provide the necessary care in a more sensitive and compassionate manner.

EDUCATIONAL OBJECTIVES: At the end of this module, caregivers should be able to:

1) Define the ten basic psychological needs of the care recipient with dementia.
2) List factors which threaten the psychological needs of the care recipient with dementia.
3) Explain how terms related to care for the elderly compromise psychosocial and psychological comfort of care recipient and caregiver.
4) Describe interventions to increase the care recipient's feelings of comfort and value.

MINI-LECTURE:

Persons with dementia may retain the ability to comprehend external events long after the ability to express themselves, in words or gestures, has diminished. As dependency needs progress, and the ability to communicate decreases, preserving the psychological needs of the care recipient becomes more important than ever. Many people fear dependency upon others almost as much as, if not more than, they fear death. The fear of losing one's sense of dignity and self worth is often greater that the fear of not having physical needs met. These values may remain long after we have lost the ability to express them. The ten basic psychological needs of people with dementia do not differ from those of any other elderly person.

These needs are:

1) To be treated as a person first, as a person with dementia second;
2) To be recognized as an adult;

3) To be treated as a unique individual;
4) For recognition and approval from others;
5) For self-confidence and respect;
6) For social interaction;
7) To preserve identity;
8) For emotional support;
9) For some influence or control over one's environment; and
10) To live, not merely exist.

There are several ways in which caregivers may contribute to care recipients' psychological "dis-ease" (or feelings of discomfort). These are usually not intentional, but are often oversights on the part of caregivers. Some examples are:

1) Failing to include care recipients in decision-making, even when it relates to them;
2) Imposing their values on care recipients, believing that they are unaware of the situation;
3) Talking to others about them and their conditions when they are present, as though they aren't even there;
4) Forcing them to conform to the caregivers' lifestyles;
5) Disregarding their previous preferences for things;
6) Forgetting to include them in social activities; and
7) Failing to insure privacy during activities of daily living.

Besides these inadvertent behaviors, there are some terms or phrases commonly used when discussing the elderly, especially those experiencing dementia, which cause psychological discomfort. They are well intentioned, but many alert and oriented elderly persons have voiced their strong objections. Some of them are:

"Once a man, twice a child." This has been a very damaging phrase which has been used throughout history to refer to an elderly person with dependency needs. The care recipient must always be thought of and treated as an adult, despite the amount of assistance needed to carry out activities of daily living. This phrase is also accepted by many elders because they believe society expects them to act like helpless children when they have reached a certain age. Caregivers may need to point out to their care recipients that they are still expected to act like adults.

"Parenting one's parent" and "role reversal." These are two other popular phrases which contribute to the psychological discomfort of those receiving care from their adult children. It is impossible for adult children to reverse roles with their parents or to become their parents. Thinking that way causes caregivers stress, too, because it means that they have lost their parents. Despite the severity of their parents' dependency needs, their roles are **not reversed**. Rather, their roles as children become **expanded**. Their roles now include the responsibility of helping their elderly parents in activities that they are no longer physically and/or mentally able to do independently. One of the ten basic psychological needs of care recipients is to preserve their identity. When adult children must make decisions for their parents, they should employ the same principles and preferences that their parents would use.

"Diapers." This is a term commonly used to refer to an incontinent brief or pad for an adult. While very appropriate for an infant or toddler, the word is most embarrassing for an elderly person. It is much more appropriate to refer to the undergarment as simply an "incontinence brief," or "incontinence pad" to insure dignity and self-esteem.

Areas of focus for caregivers to increase feelings of comfort and value in care recipients should include:

1) Identity
    - Respect role in family
    - Allow or support prior personal preference
2) Independence
    - Assess ability and willingness to participate in own care
    - Emphasize assets and strengths
    - Give reinforcements and strengths
3) Privacy
    - Create a safe place for care recipient to be alone
    - Manipulate environment as much as possible
4) Stability
    - Provide consistency
    - Build and maintain trusting relationship

5) Meaningful living
    - Give as many choices as suitable
    - Give some responsibilities as limitations will allow
    - Seek opinions and advice
    - Include in problem solving

6) Reason for living
  - Establish positive reasons for living
  - Promote feeling that care recipient's life is important to others

AUDIO-VISUAL REINFORCEMENT:

"Living with Grace" produced and distributed by Video Press, University of Maryland, School of Medicine, Suite 133, 100 Ren Street., Baltimore, MD 21201

"Even These May Forget." (A Pastoral Care Challenge: Training Program for Clergy) produced and distributed by University of Pittsburgh Medical Center, Alzheimer's Disease Research Center, Iroquois Building, 3600 Forbes Ave., Pittsburgh, PA 15213.

EXPERIENTIAL LEARNING:

1) Ask the group to list at least five reasons they look forward to getting older; five reasons they fear getting older; and five specific preferences they want honored even if they are unable to make decisions for themselves.

REFERENCES AND SUGGESTED READINGS:

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Maxcine Maxfield is gratefully acknowledged as the major contributor to this module.

Module 16: Drug Treatment: Side Effects and Misuse

GOALS: To increase knowledge and understanding of the drugs currently used in treating symptoms of Alzheimer's Disease, their side effects, and the danger in not properly taking medications.

RATIONALE: Caregivers who know about the drugs that are available, their potential side effects, and the importance of taking medications in the most appropriate manner are better prepared to handle any threatening situations or problems that may arise.

EDUCATIONAL OBJECTIVES: At the end of this module, caregivers should be able to:

1) Describe the drugs that are currently available to treat the symptoms of Alzheimer's Disease, recognizing the benefits and risks involved.
2) Understand the physiological changes the body goes through due to aging and how it affects the way the body uses drugs.
3) Understand the difference between a drug reaction and a drug interaction and ways to avoid them.
4) Define compliance and non-compliance, and describe the various forms of non-compliance.
5) List the reasons why people don't follow medical instructions and what can be done to improve compliance.
6) Speak to their doctors and pharmacists and get the information they need about medications and their correct use.

MINI-LECTURE:

Treating Alzheimer's Disease and Psychiatric Symptoms with Drugs

No drug has been proven highly effective in the treatment of Alzheimer's Disease symptoms. Several drugs are being studied to see if they can either improve memory and other cognitive symptoms of AD or slow down the progression of the disease. None of these drugs cure or stop the progression of the disease.

Neurotransmitter systems are message carriers which transmit information from one nerve cell to another. Several of these systems are defective with AD. One, the cholinergic system, is essential to memory and learning. Researchers have discovered abnormalities in the cholinergic systems of persons with AD. The drugs being researched that might positively affect the cholinergic system include: Tacrine (Cognex), Mentane (velnacraine maleate), cycloserine, and linopirdine. Research is directed toward persons with AD who show mild to moderate memory impairment. Tacrine (Cognex) has received the greatest attention and was recently approved by the FDA. Now any physician can prescribe it. This drug does not improve memory or bring people to a previous level of ability. It may help the care recipient to stay at their current memory level. The drug is started at a low dosage and evaluated every six weeks before it is increased. The cost is approximately $100 per month. The side effects experienced by its use may include: urinary frequency, nausea, vomiting, diarrhea, decreased appetite, and weight loss (up to 2 lb./month). An infrequent, but very serious side effect, is a head to toe rash. If this should occur stop taking the medicine immediately and notify the doctor. The most serious drawback of Tacrine is liver damage. For this reason, the patient must be seen frequently by a doctor.

Individuals with dementia may become depressed because they are not able to do the things they used to. Their caregivers may also experience depression due to the stress and burden of caregiving. Antidepressant drugs are often prescribed to eliminate the symptoms associated with depression. Frequently prescribed antidepressants include: Elavil, Pertofrane, Sinequan, Prozac, and Desyrel. While improvement in sleeping patterns and appetite should occur within the first few weeks, it takes longer to observe improvement in mood. During the early weeks of the treatment, persons with AD who are being treated with anti-depressants may experience some side effects including: dry mouth, constipation, dizziness, tremors, hallucinations, or paranoid behavior. Some of these symptoms are also seen with dementia and are not necessarily the result of medication. Due to physical changes occurring with aging, urinary retention and confusion may also be experienced.

These are some things to be aware of anytime a new medication is prescribed. The elderly are generally more sensitive to medications. Those with the highest potency (e.g., Elavil) should be avoided whenever possible because of the damaging effects it may have on memory. Much thought must be given as to whether a drug will prove to be more harmful than helpful. Caregivers have to be on constant alert for any changes. It is a difficult job, but the recipients' health and lives are at stake.

Another group of medications that may be used to treat depression is monoamine oxidase inhibitors (MAOIs), e.g., Phenelzine, Tranylcypromine. While the person with AD is taking these medications, and for two weeks after stopping the medications, there are specific restrictions. Alcohol, caffeine, and certain foods (e.g. red wine, poultry, aged pasteurized cheese) should be avoided. If the care recipient is willing to stop eating the restricted items, MAOIs may be an effective treatment option. Over the counter (OTC) drugs are those that are bought and used without a prescription. When taking either antidepressants or MAOIs, the use of OTC drugs should be discussed with the doctor or pharmacist.

Agitated behavior, severely disturbed thinking, hyperactivity, and hostility are often treated with neuroleptics (antipsychotic drugs), e.g., Thorazine, Haldol, or Prolixin. Studies have shown that 60-70% of people with AD who experienced a variety of underlying disorders, demonstrated good to excellent responses to neuroleptics. Even with good results, side effects may be a problem in the elderly. Sometimes agitated behavior can worsen with neuroleptic treatment. Other possible side effects associated with neuroleptics include: raised or lowered blood pressure, drowsiness, inability to sleep and confusion at night, restlessness, loss of balance, difficulty talking, and other symptoms (such as muscle rigidity, involuntary movement of the tongue, mouth, face, and neck). Another disadvantage with some neuroleptics is the worsening of cognitive functioning. If the care recipient is on a high potency antipsychotic (e.g., Haldol), be careful not to allow them to become overheated. Also, avoid hot baths to prevent heat stroke.

Benzodiazepines are antianxiety or hypnotic drugs such as Valium, Serax, Ativan, Dalmane. They are used for short-term relief from anxiety, tension, fatigue, or agitation. Some of these drugs are not recommended for the elderly because they are long-acting and can lead to a build up of side effects. Possible side effects with these drugs include: dizziness, confusion, depression, disorientation, and slurred speech.

The decision to use a medication in psychiatric treatment is a major step for anyone with AD. Although they can be helpful in managing behavioral problems, it may take weeks to see improvement. Side effects, on the other hand usually occur immediately. It is important to be aware of possible side effects and have good communication with the doctor. In this way an informed decision can be made about using the various types of drugs. The caregiver must decide whether the side effects outweigh the previous problem behavior. All these drugs should be used at lower dosages and for shorter time frames in older persons. If side effects occur, it is very important not to stop the medications suddenly without checking with the doctor or pharmacist immediately.

Drug Side Effects

Although older Americans represent 12 percent of the U.S. population, they consume 32 percent of all prescription drugs, which is more than 400 million prescriptions a year. Self-medication with OTC drugs is the most common form of medical care among older adults. OTC drugs are often used to relieve minor symptoms such as upset stomach, constipation, aches and pain, cough, or fever. By age 65, most older adults are suffering from at least one chronic disease or illness. For instance, almost half all persons age 65 and older have arthritis and approximately 40 percent have high blood pressure. Multiple health problems often result in older people taking several drugs simultaneously. The average older person takes about six medications a day -- 3.4 prescriptions and 2.6 OTC drugs. Elderly women take more prescription and OTC drugs than men.

When used properly, medicines can be helpful in treating the symptoms associated with disease and illness. On the other hand, older adults may be at special risk for problems related to their medications. Due to physical changes that occur with aging, medications may affect older adults differently. Problems may occur due to adverse reactions to medications, interactions with other drugs, foods, or alcohol, or taking medications improperly. The care recipient may also be taking medications to treat other health problems.

As a caregiver, you need to understand the possible side effects that may occur with the use or misuse of medications. This is true not only for preventing problems for the care recipient, but also in maintaining your own health.

As we age, natural physical changes occur in our bodies which may affect the way medications are absorbed, distributed, metabolized, and excreted. As the body changes, drug effects become less predictable. Changes in the digestive tract, such as loss of muscle tone and less stomach acid, can affect the absorption of the medications or how quickly they enter the blood stream. The loss in body weight generally experienced as we age may influence the amount of medicine we need to take and how long it remains in our bodies. Because the circulatory system also slows down, medications may not get distributed as quickly throughout the body. The liver and kidneys are important organs responsible for breaking down and removing most drugs from your body. The liver and kidneys also work more slowly as we age. As your circulatory system slows down, your liver may not break down the drugs as rapidly. Your kidneys may have trouble eliminating the wastes, including drugs.

Medications may affect older adults differently because of these physical changes. It is important to remember that "drugs" are not just prescription medicines (those ordered by a doctor and obtained from a pharmacist), but OTC medicines as well. Prescription drugs are usually more powerful and have more side effects than OTC drugs. However, many OTC drugs contain strong agents, and when large quantities are taken, can equal a prescription dose. Alcohol is also considered a drug. It is a good rule of thumb to avoid drinking alcohol while taking any other drugs.

Medicines are meant to be helpful, but no medication is completely free of adverse drug reactions or side effects. The seriousness of side effects depends on the type of medication, the amount taken and the person's body chemistry. They may range from bothersome to life threatening. Some side effects may occur immediately after starting the drug, or they may develop over time. Some common side effects from medications include: restlessness, confusion and memory loss, sleeping disorders, depression, constipation, and weight loss. These side effects are a particular concern for caregivers of individuals with dementia and AD. Several are the same symptoms associated with dementia or part of "normal aging." These similarities can result in adverse drug reactions going unnoticed. Not being warned of a side effect can prompt the person with AD to stop taking their medications before they should. This can cause complications that may be worse than the side effects.

There are certain steps that may be taken to minimize adverse drug reactions:

- Find out as much as possible about every medication (including its name, purpose, dosage, frequency, and possible side effects) from your physician or pharmacist before taking the medication. If a side effect occurs, report it immediately to the physician.

- Advise the physician of any allergies or reactions from previously used drugs.

- Read the labels and question the physician or pharmacist about information you do not understand.

- Note any difficulties or changes that develop and report these to the physician immediately. Alternative medications may be available that cause fewer side effects. Do not assume adverse effects are necessarily "natural" for older adults.

When medications are mixed with other drugs, foods, coffee, cigarettes, or alcohol, harmful drug interactions (change in the effectiveness or safety of a medication) may occur. Combining these items may increase or decrease the effectiveness of the medication or keep it from working at all. One drug may interact with another, occasionally creating serious medical problems. For example, laxatives may decrease absorption of other drugs. Food and medicine are absorbed, distributed, metabolized, and secreted in similar fashions. What you eat or drink may impair the effectiveness of the drug. The presence of food in the digestive track may affect the rate at which a drug is absorbed. Also, the body's tolerance to alcohol decreases with age, so interactions may be more significant. Cigarettes can diminish the effectiveness of medications. Finally, caffeine, which is found in coffee, tea, soft drinks, chocolate, and some medications, may also affect the action of some drugs.

To help prevent drug interactions:

- make sure the doctor involved is aware of all medication the person is taking (prescription and OTC). It's often helpful to bring the medications with you to the doctor's office. You might want to keep a written record of all current medications, including name, dosage, and starting date. This record will help in communicating with the doctor and/or pharmacist should a serious interaction occur.

- ask the pharmacist to check for interactions between other drugs as well.

- ask what foods, drinks, medications, or activities should be avoided while taking the medication.

- ask for suggestions on adjusting/coping if the eating habits or daily routine of the care recipient will have to change.

Drug Use and Misuse (Compliance and Non-Compliance)

The elderly are often taking medications for a variety of purposes. There are several reasons why they may be misusing their medications, often unintentionally. The term "non-compliance" is broadly defined as:

1) Taking too little or too much of the medication;
2) Discontinuing its use prematurely;
3) Eating foods or drinking alcohol which negatively interacts with the medication; and

4) Sharing prescriptions, or using old medications prescribed for a previous illness.

Since, older adults may be taking several medications because of chronic illnesses, they are at a greater risk for non-compliance. Older women may be at an even greater risk because of their higher levels of drug use. It is estimated that up to 50% of individuals with AD do not take their medications properly. Compliance is defined as "the extent to which a person's behavior (in terms of taking medication, following diets, or executing lifestyle changes) coincides with medical or health advice." It is the degree to which medical recommendations are followed. Compliance rates are often based on the number of doses prescribed per day. For prescriptions taken four times a day, only 25-30% of people take medications properly, for three times a day it goes up to 59%, and twice a day rates are around 75%. Even if medication is taken only once a day, the compliance rate is only 83%.

Non-compliance is identified by the types of situations in which it may occur.

Errors of omission -- failure to have prescriptions filled and/or omitting doses. With some illnesses, a person may not experience symptoms (e.g., high blood pressure) so they may not understand the need to have the prescription filled or refilled. One in three African Americans has high blood pressure, and African American women over age 65 are more at-risk for high blood pressure. Persons experiencing memory loss and confusion may not have taken their medications properly or at all. It may also be necessary to confirm whether the medicine has been swallowed.

Overdosing (intentional and unintentional) -- taking more drug than is prescribed. Some people use different physicians for different ailments (possibly receiving separate prescriptions from each doctor). Some use more than one pharmacy for filling prescriptions. These practices contribute to the risk of taking a double dose of a medication and prevent the physicians and pharmacists from monitoring an individual's overall medication plan. For some medications it is more difficult to determine a correct dose. In addition, certain conditions may intensify the possibility of overdosing. For instance, if someone is frightened during an asthma attack, he or she may improperly use an inhaler and obtain too much/little of the medication. People may think using OTC drugs along with a prescription will help relieve symptoms quicker, but it may in fact result in overdosing from the combination. Taking too much can cause an overdose; taking too little can prevent the medication from working.

Medications taken for the wrong purpose -- inappropriate use of prescription or OTC medications. About half of all drugs prescribed for older persons include some form of sedative. Lack of knowledge about OTC drugs and the effects of combining them could result in more complications. It is important that the caregiver describe behavior problems and symptoms accurately and completely to the physician so a proper drug can be prescribed. Often the care recipient does not complete a drug treatment plan and saves the unused medication. If you are experiencing similar symptoms from a previous illness, you may think a left-over drug will be effective with the current illness. Rather than take the leftover medication, you should talk with the doctor first. It may not be the same illness, the drug may be outdated, and/or other drugs could cause an interaction. The best thing to do is complete the drug schedule prescribed. Do not keep the medicine for use at a later time.

Errors in frequency of dosing -- mistakes in the timing of doses. The number of times a drug is taken and the time of day it is taken, (i.e., before meals, with food, one hour before meal) can be critical to a drug's effectiveness. Often instructions are unclear (e.g., What does "take as needed" mean ? Does "four times a day" mean with meals and at bedtime ? What do you do if you miss a dose? What if the person refuses to take the medication ?) Giving medications in a specific way at specific times of the day will help reduce conflicts. Generally, if you miss a dose, do not automatically double the dosage later. As the disease progresses, you may need to assume full responsibility for giving medications.

Using drugs prescribed for others -- using drugs of friends or relatives in the hope that these drugs will help, since symptoms are similar. To save time or the cost of an office visit or trip to the pharmacy, older adults may use the prescriptions of others. It is unsafe to self-medicate without checking with the physician. Although symptoms may seem similar, the illness may not be. Taking someone else's medication may create even more complications. This practice should always be avoided.

Incorrect administration of medication. If the person has tremors, it may be necessary for you to assist them in taking their medications. When using eye drops, be sure you know exactly how many drops to use. If using more than one drop, wait two minutes between each drop (the eye can hold only about three drops -- any more will run out). If they cannot swallow or they spit out the pills, it is generally acceptable to crush a tablet and mix it with applesauce. However, the acidity of the applesauce may decompose some drugs. Again, a good general rule is to check with the pharmacist before making these decisions. If this is a problem, some medications may be available in liquid form.

There are several reasons for people to be non-compliant. Complex drug schedules interfere with daily living, not only for the care recipient but the caregiver as well. A schedule may be difficult to maintain if assistance during the day is not easy to come by. If the person is on several medications, maintaining the proper schedule may seem like a full-time job. The physician needs to be aware of any eating or sleeping problems in order to adjust the medication routine. Some people just stop taking the prescribed medication rather than discussing other possibilities with the doctor or pharmacist.

Complex or complicated drug treatment plans. Caregivers may need to keep track of several drugs, not only for themselves, but also for the care recipient. If you're on more than one drug, juggling the times for administration may become very complicated (e.g., with meals, one hour before eating, four times a day).

Misunderstanding or misinterpreting instructions. Studies suggest that older women of color will have more problems communicating with the doctor because of differences in language, perception of illness, and expectations. With all the issues caregivers must deal with, verbal instructions may not be remembered. They may for example focus instead on directions given for previous medications. In a stressful situation such as illness, it is often difficult to remember verbal instructions. Written instructions are more helpful, since they can be referred to at a later time.

Visual and hearing losses. As people get older, they have more visual problems and may not be able to read labels on prescriptions. There are also changes in the ability to see certain colors (blue and green), which are often used on labels or as pill/capsule colors. Glare intolerance increases with age, and if non-glare tape is not used on bottles, the person may not be able to read instructions. As we age, we have a greater chance for hearing loss. Rather than being embarrassed about a hearing loss, persons with AD often will not ask the physician or pharmacist to repeat instructions or ask for clarification. Older adults may have particular trouble hearing females because of the higher pitch of their voices.

Economic constraints. About 5% of elderly people with AD say they cannot afford their medications. Some may be forced to choose between buying their medications, paying bills, buying food, or they may take a medication once a day when it is prescribed for three times a day, hoping it will last longer. Many prescription drug manufacturers make their medications available free of charge to older people who do not have the means to pay for them. The physician must make the contact with the company to obtain the drugs. Caregivers in economic need can ask their physicians about the Pharmaceutical Manufacturers Indigent Patient Program.

Memory impairment. A person with AD might forget when medications were taken and, as a result, take twice as much or none at all. When forgetfulness or confusion is a major issue, supervision of drug taking should be arranged. Memory impairment may be intensified with other drugs.

By not taking medications as intended, consequences of drug non-compliance may occur. If persons with AD are not receiving the proper dosage, they are being deprived of expected health benefits. It may take weeks to see improvement with some drugs. This could result in a relapse of the condition. Timing and dosage of a drug result in the person staying within a therapeutic range to obtain the greatest possible benefits. Due to physiological changes, excessive doses or taking medications more frequently than needed could result in toxicity (drug having harmful rather than therapeutic effect). Changes in the body as we age also increase the possibility of risk for addiction/dependency. If the person is not taking medications properly, and the physician is not aware of this, the physician may assume the dosage prescribed is not correct. An increase in dosage may result in greater side effects.

The physician and pharmacist have a major role in detecting non-compliance, but the caregiver has an even greater opportunity to observe possible non-compliant behavior. The caregiver needs to be aware of increased confusion, memory loss, agitation, depression, changes in sleep patterns, and altered eating habits. Be aware of any physical changes, including increased falls, changes in gait, or changes in speech. Certain medications, especially when taken together, have the potential to create side effects similar to AD symptoms. It is critical that caregivers be aware of their care recipients' medication cycle and let the physician know about any changes that have occurred.

The caregiver can take action to improve compliance by anticipating the future decline. Early on in the disease, memory aids may be used (e.g., placing a small cup on the kitchen table as a reminder to take medications; organizing the environment so that medications are always in the same place; posting written reminders on the refrigerator or by the telephone--"Did you take your medicine?" In clear, simple language, help the care recipient to understand the kinds of medications being taken and why they are needed. Offer clear instructions, such as "Here's the pill for your high blood pressure. Put it in your mouth and drink some water."

Stay organized! It is absolutely essential that caregivers stay organized. Separate pills into a plastic container with small compartments labeled "day" and "evening" or "Monday", "Tuesday," etc., to help track medications. Some may find it useful to give medications in individual cups or envelopes, or to keep a calendar and check off each dose as it is taken. There are other compliance packaging systems available from the pharmacist including: medication calendars, color-coded bottles, clock faces (which help those who can not read or have visual problems), blister cards (daily dose for month packed in pop-out container marked for calendar day), large print or symbols on prescription bottles for visually impaired, coding system for illiterate persons with AD or those who do not read or speak English (e.g., symbols of sunrise, full sun, sunset to represent times; plate and utensil symbols to show whether they should take medication before or after meals). Naturally, as the disease progresses, caregivers will need to take full responsibility for giving their care recipients various medications.

Compliance can also be maintained by obtaining good information from the physician and pharmacist. Caregivers should ask about:

- drug name, strength, and dosage forms;
- why prescribed;
- when to take (e.g., time of day);
- how to take (e.g., orally, inhale, suppository);
- how long to take (e.g., 10 days, rest of life);
- special precautions (e.g., avoid sun, restrict activities);
- dietary precautions (e.g., take with meals, avoid dairy products);
- what to do if dose is forgotten;
- storage conditions (e.g., refrigerate);
- what written materials are available (serve as reminders when directions are complicated).

AUDIO-VISUAL REINFORCEMENT:

" As the River Flows...Medication and the Elderly: Patient Compliance," produced and distributed by Institute for Health Systems Management, 5 West Nine Mile Road, Highland Springs, VA 23075, (804) 737-6699 or (800) 736-3704, (10 day rental/$99, purchase/$195).

"The Medicated Generation," produced and distributed by Parke-Davis. Available through Modern Mass Media, Inc., P.O. Box 950, Chatham, NJ 07928, Att: Film Library (201) 635-6000. Offered free of charge but users are responsible for return shipping costs.

"Drug Related Risk Factors" and "Epidemiology of Drug Use: Polypharmacy and Adverse Drug Reactions in the Elderly" (2 videos in the series, "Misadventures with Medications by Older Adults: Appropriate Use," V0261 and V0260) produced and distributed by the Northwest Geriatric Education Center, 1910 Fairview Avenue E., #203, Seattle, WA 98102 (206) 685-7478.

"Drug Misuse in the Elderly," produced by KCTS-TV. Distributed by the Northwest Geriatric Education Center, 1910 Fairview Avenue E., #203, Seattle, WA 98102 (206) 685-7478.

EXPERIENTIAL LEARNING:

1) If the training group is very large, the trainer should ask participants to form smaller groups for discussion purposes. Otherwise the trainer should lead the entire group in discussing one or more of the following topics:

A. The drugs being studied to improve memory in individuals with dementia,
B. The benefit of Tacrine (Cognex) and possible side effects,
C. The physiological changes that occur with aging and the overall meaning of drugs,
D. The possible adverse drug reactions and drug interactions that may occur and their particular relevance to those with dementia and AD,
E. The difference between compliance and non-compliance, the types of non-compliance, six reasons why non-compliance may occur, and how the caregiver can improve compliance.

2) Distribute copies of the one-page handout, Commonly Prescribed Medications by Category, and lead the group in listing the side effects that may occur with drugs in each category.

3) Role play a situation in which a caregiver is questioning a doctor or pharmacist to learn about possible adverse drug reactions and drug interactions.

4) At the end of this module is a handout from the National Institute on Aging. Distribute copies of the handout, and review the basic rules for safe drug use.

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Commonly Prescribed Medications by Category:

Neuroleptics (Antipsychotic)

Clozaril (Clozapine)
Compazine (Prochlorperazine)
Haldol (Haloperidol)
Inapsine (Droperidol)
Loxitane (Loxapine)
Mellaril (Molindone)
Moban (Molinodone)
Navane (Thiothixene)
Orap (Pimozide)
Prolixin (Fluphenazine)
Serentil (Mesoridazine)
Sparine (Promazine)
Stelazine (Trifluoperazine)
Taractan (Chlorprothixene)
Thorazine (Chlorpromazine)
Tindal (Acetophenazine)
Trilafon (Perphenazine)
Vesprin (Triflupromazine)

Antidepressants

Asedin (Amoxapine)
Aventyl, Pamelor (Nortriptyline)
Desyrel (Trazodone)
Elavil (Amitriptyline)
Lithonate, Lithane (Lithium)
Ludiomil (Maprotiline)
Marplan (Isocarboxazid)
Nardil (Phenelzine)
Norpramin (Desipramine)
Parnate (Tranylcypromine)
Prozac (Fluoxetine)
Sinequan (Doxepin)
Surmontil (Trimipramine)
Tofranil (Imipramine)
Vivactil (Protriptyline)

Benzodiazepines (Antianxiety/Hypnotics)

Anytal (Amobarbital)
Atarex (Hydrooxyzine)
Ativan (Lorazepam)
Buspar (Buspirone)
Centrax (Prazepam)
Dalmane (Flurazepam)
Doriden (Glutethimide)
Equanil, Miltown (Meprobamate)
Halcion (Triazolam)
Librium (Chlordiazepoxide)
Nembutal (Pentobarbital)
Noctec (Chloralhydrate)
Noludar (Methyprylon)
Paxipam (Halazepam)
Placidyl (Ethchlorvynol)
Restoril (Temazepam)
Seconal (Secobaribital)
Serax (Oxazepam)
Tranxene (Clorazepate)
Vistaril (Hydroxyzine)
Valium (Diazepam)
Xanax (Alprazolem)

National Institute on Aging

Age Page

Safe Use of Medicines by Older People

Drugs can be wonderful tools for the care of patients of all ages. In fact, the growth of our population over the age of 65 can be attributed at least in part to the availability of effective medicines and vaccines. But in older adults drug use may have greater risks, especially when several drugs are taken at one time.

People over 65 make up 13 percent of the American population, yet they take 30 percent of all prescription drugs sold in this country. As a group, older people tend to have more long-term illnesses—such as arthritis, diabetes, high blood pressure, and heart disease—than younger people. And because they often have a number of diseases or disabilities at the same time, it is very common for them to be taking many different drugs.

In general, drugs taken by older people act differently from the way they do in young or middle-aged people. This is probably the result of the normal changes in body makeup that occur with age. For example, as the body grows older, the percent of water and lean tissue (mainly muscle) decreases, while the percent of fat tissue increases. These changes can affect the time a drug stays in the body and the amount absorbed by body tissues.

The kidneys and the liver are two important organs responsible for breaking down and removing most drugs from the body. With age, these organs begin to function less efficiently, and thus drugs leave the body more slowly. This may account for the fact that older people tend to have more undesirable reactions to drugs than do younger people.

It is important to remember that "drugs" include not only prescription medicines (those ordered by a doctor and dispensed by a pharmacist) but over-the-counter (OTC) medicines as well (those bought and used without a prescription). Drugs prescribed by a doctor are usually more powerful and have more side effects than OTC medicines. Yet many OTC drugs contain strong agents, and when large quantities are taken, they can equal a dose that would normally only be available by prescription.

Some substances, including vitamins, laxatives, cold remedies, antacids, and alcohol, can also lead to serious problems if used too often or in combination with certain other drugs.

There is much that you and your family can do to reduce the risks of drug use. By learning about the drugs you take and their possible side effects, you can help bring about safer and faster treatment results. Some basic rules for safe drug use are as follows:

- Take exactly the amount of drug prescribed by your doctor and follow the dosage schedule as closely as possible. If you have trouble or questions, call your doctor or pharmacist.

- Medicines will not produce the same effects in all people. Never take drugs prescribed for a friend or relative, even though your symptoms may be the same.
- Always tell your doctor about past problems you have had with drugs (such as rashes, indigestion, dizziness, or lack of appetite). When your doctor prescribes a new drug, be sure to mention *all* other medicines you are currently taking—including those prescribed by another doctor and those you buy without a prescription.
- Keep a daily record of the drugs you are taking, especially if your treatment schedule is complicated or you are taking more than one drug at a time. The record should show the name of the drug, the doctor who prescribed it, the amount you take, and the times of day for taking it. Include a space to check off each dose as you take it. Keep a copy in your medicine cabinet and one in your wallet or pocketbook.
- If child-proof containers are hard for you to handle, ask your pharmacist for easy-to-open containers. Always be sure, however, that they are out of the reach of children.
- Make sure you understand the directions printed on the drug container and that the name of the medicine is clearly printed on the label. Ask your pharmacist to use large type on the label if you find the regular labels hard to read.
- Discard old medicines; many drugs lose their effectiveness over time.
- When you start taking a new drug, ask your doctor or pharmacist about side effects that may occur, about special rules for storage, and about foods or beverages to avoid. Pharmacists are drug specialists and are able to answer most questions about drug use.
- Always call your doctor promptly if you notice unusual reactions.
- New information about drugs and how they affect the older user is coming to light daily. You should occasionally review with your doctor the need for each medicine.

Remember that a chemical agent strong enough to cure an ailment is also strong enough to cause harm if it's not used wisely. Although you should never stop taking medicines without medical advice, if you feel any drug is doing more harm than good, don't be afraid to discuss the matter with your doctor. He or she may be able to substitute another medicine that will be effective.

Other Resources

For more information on the safe use of medicines, contact the Elder Health Program, University of Maryland School of Pharmacy, 20 North Pine Street, Baltimore, MD 21201; and the Food and Drug Administration, Center for Drug Evaluation and Research, Consumer and Professional Affairs (HFD-365), 5600 Fishers Lane, Rockville, MD 20857.

To learn more about health and aging, write to the National Institute on Aging Information Center, P.O. Box 8057, Gaithersburg, MD 20898-8057. The NIA distributes free *Age Pages* on a number of topics.

1991

Module 17: Alcoholism and Alcohol Abuse: What African American Family Caregivers Need to Know About Risks

GOAL: To educate family caregivers about alcoholism and alcohol abuse, the adverse consequences and their own risks for substance abuse, as well as the risks to the elderly care recipient.

RATIONALE: Caregivers who are aware of the risks for alcoholism and alcohol abuse are less likely to become abusers of alcohol. Furthermore, caregivers who are well informed about the risks are more likely to seek help for themselves or family members.

EDUCATIONAL OBJECTIVES: At the end of this module, caregivers should be able to:

1) Define alcohol abuse and alcoholism, and describe their prevalence in the elderly African American population;
2) Understand the impact of alcoholic behavior on the alcoholic and other family members;
3) Appropriately confront the family member who is abusive to himself or other family members;
4) Recognize the role of each family member in the dysfunctional situation and how they can take better care of themselves;
5) Understand and overcome some of society's stereotypical myths and labels about alcoholism and alcohol abuse in older adults;
6) Identify risk factors associated with alcohol abuse and dependency; and
7) Develop a plan for appropriately referring an addicted family member to treatment.

MINI-LECTURE:

Alcoholism: Its Prevalence and Consequences

Alcoholism is a chronic disease that is often progressive and fatal. It is characterized by:

1) Continuously or periodically impaired control over drinking;
2) Preoccupation with the drug, alcohol;
3) Use of alcohol despite adverse consequences; and
4) Distortions in thinking, most notably denial.

Alcoholism, as a disease, depends on the consumption of alcohol. Who gets the disease, the quality of treatment available and the prospects of recovery depend on one's lifestyle, social status, and available economic resources.

Recent estimates are that 10.5 million Americans exhibit some symptoms of alcoholism or alcohol dependence. An additional 7.2 million are high risk drinkers, but do not show symptoms of physical dependency. During the past decade, there has been a heightened vulnerability to drugs and alcohol in the older adult population. According to many experts, 10 to 15% of the over-60 population is affected by alcoholism and/or drug dependency.

The elderly are particularly vulnerable to experiencing problems with alcohol and other drugs because of their place in the life cycle. While some elderly problem drinkers are alcoholics, others simply have an occasional problem with alcohol. Drinking problems among the elderly, however, shorten their life spans, reduce the quality of their lives, and make them increasingly more dependent on family members and service care providers.

The consequences of alcohol abuse have been well documented. In the African American community, the problem is even more pronounced. Some estimates suggest that almost half of all Black people are directly affected by the problem of alcohol and other drug abuse.

Alcohol is a primary factor in five of the seven most serious causes of deaths among African Americans, according to the Office of Minority Health at the U.S. Department of Health and Human Services. Alcoholism has been identified by the National Black Alcoholism Council as Black America's number one health problem leading to disease and death. Excessive consumption of alcohol (more than two drinks a day) can raise cholesterol levels and contribute to high blood pressure, the recognized silent killer in the Black community. High blood pressure is also an important factor in heart disease, certain cancers and diabetes. The greatest single cause of cirrhosis of the liver--the third highest ranked cause of death for African Americans -- is alcohol abuse. In addition, alcohol related accidents result in a high rate of fatalities.

Alcoholism is a heavy burden to overcome; it is an even greater burden to live with. African American family members must learn how to break the cycle of addiction, get help for themselves and begin the job of repairing the family. To do this, the family caregiver must get the facts about the impact of alcoholism and alcohol abuse on the individual, the family and the community. African American family caregivers must learn to talk about racially sensitive issues and cultural pain. In this way they can grow in self-esteem and self-awareness, put away old hurts and resentments, and move on to a loving acceptance of themselves and their addicted family members.

Caregiving can be a stressful and emotional experience. When caring for an elderly family member with substance abuse problems, the caregiver must be careful not to neglect his or her own needs. The caregiver will not have the inner resources to care for the addicted family member if he has not first resolved his own issues. It's important to understand the emotional impact of alcoholism and the role of each family member. In addition, the caregiver must realize that the stress of caring for a family member with alcoholism or alcohol abuse problems increases his or her own risk. The caregiver must guard against using alcohol or other drugs in response to the strains they may be experiencing.

Alcoholism and Alcohol Abuse From A Historical Perspective

In traditional African cultures, drunkenness was discouraged and almost universally despised. Although widely used, the role of alcohol in community life was determined and dictated by social norms and rules. Many formal and informal means of social control were in place, and people were respected for moderate drinking.

When the Africans came to America, they found alcohol easily accessible, Yet, their traditional patterns of alcohol use prevailed and drinking among Black people was rarely a problem. As incomplete as health statistics are about Blacks from 1850 to 1855, the U.S. Census Office supports these historical reports.

Drinking was encouraged among the slaves during the holidays on the master's plantation or property. Permitting the slaves to drink on holidays portrayed the master as kind-hearted. It also allowed the master to enjoy holiday festivities without having to worry about the slaves running away or plotting insurrections.

The behavior of Blacks during the Reconstruction period -- including the drinking of alcohol whenever they wanted to -- was their response to emancipation. This led to many stereotypical perceptions of Blacks as excessive drinkers, lazy, and dangerous people.

Massive migration of Blacks from the South to the North was fueled by the promise of a better life than was possible in the South. The cultural norms and values of Blacks were severely challenged by the massive relocation and led to the establishment of The National Urban League to address the needs of Blacks in an urban environment.

During the period of migration to the North, Blacks used drinking as a way of relaxing and relieving the stresses of the prior week. The patterns of social drinking continued for weddings, funerals, wakes, and holidays. In addition, neighborhood taverns and speakeasies became popular as gathering places for the large numbers of Blacks who came together for socialization and drinking. The neighborhood tavern soon became the focal point of community politics as well.

During the early 1900's some Blacks promoted the benefits of abstaining from alcohol and preached the immorality and sinfulness of drinking. They were told that alcohol use was contributing to negative stereotyping of Blacks and therefore was harmful to the Black community as a whole. Each individual was charged with the personal responsibility of abstaining from drinking alcohol, especially as sobriety was seen as the Black man's pass to freedom. Later, and along these lines, the Rev. Jesse Jackson is credited with saying, in essence, "We may run, walk, march or crawl to freedom, but we will never stagger to freedom." The profits from the sale and marketing of alcohol, including bootlegging, were too enticing, however, and few Blacks were converted to abstinence.

The use of alcohol among Blacks increased dramatically after Prohibition. A 1928 Metropolitan Life Insurance Company report documents that the death rate per 100,000 from alcoholism steadily increased among Black policy holders from 1918-1927.

The Depression period introduced a wave of "rent parties." Music, entertainment, liquor and food were exchanged for money to pay the rent, or buy food for a less fortunate relative or friend. The speakeasy, from which many Black musicians and singers emerged, also was a product of this era.

Because of the intense racial discrimination present in American society, a Black "outlaw" mentality regarding alcohol began to develop. Because they were not given the same rights and privileges as those of the mainstream society, Black Americans began to profit from the sale of illegal alcohol and other drugs, just as their white counterparts did. Shortly after Prohibition, laws were enacted to further limit access to and consumption of alcohol by Blacks.

Today, many activists in the fight against alcohol and drug abuse believe that alcohol and other drug abuse contributes to many of the social problems plaguing the Black community (e.g., the lack of adequate housing, jobs, health care, and education). The Black family must assume responsibility for decreasing the damage by alcohol and other drug abuse in the Black community. A successful fight against chemical abuse can result in significant progress against the other serious problems that hold the Black community back. The Black family has much to lose or gain by the results.

Common Alcohol Dependency Types

Common among older adults are three types of alcohol dependency: **early-onset**, **late-onset**, and **intermittent use**. The simplest of these to explain is **intermittent use**. The term refers to a history of periodic episodes of heavy drinking, also known as binging.

Early-onset dependency refers to the alcohol dependency of an elderly person aged fifty or older for whom alcohol became a problem at an early age. The early-onset alcohol dependent elderly person will have exhibited some, if not all, of the following warning signs of alcohol problems: mood changes, inconsistent behavior, secretive behavior, lying, memory lapses, confusion, frequent falls, poor health, poor eating habits, poor hygiene, isolation and abusive behavior. About two-thirds of older adult alcoholics are believed to be of this type.

The early stage of alcohol problems is often characterized by a high tolerance for liquor, i.e., a large quantity of alcohol can be consumed without outward behavioral effects. As the person ages, however, tolerance decreases because the rate of alcohol breakdown in the body is slowed.

Late-onset alcohol dependency usually occurs in the older adult when a major loss has occurred. The death of a spouse or significant other, loss of the major source of income to the family, retirement, or being forced out of a job can all precede the onset of alcohol dependency in late life. Some elderly adults begin drinking in response to a major event in their lives. Emotional and physical pain, as well as feelings of shame, anger, and loneliness may also cause an older adult to begin using alcohol to cope. It is estimated that about one-third of older adult alcoholics and alcohol abusers are of this type.

Working with the late-onset alcohol dependent individual may be somewhat easier for the family caregiver. Family values and strengths are already in place to cope with outside forces that threaten the family. In addition, the late-onset drinker may be conflicted about his values or beliefs regarding drinking and the desire to reduce pain and other negative feelings with alcohol. The prognosis for late-onset alcohol problems brought on by stress is very good when appropriate treatment and support is available.

Effects of Alcohol and Alcohol Abuse

Emotional. Most alcoholics or alcohol abusers deny their addiction or problem with the drug. The addicted person will generally argue that he is in complete control of how much and when he takes a drink. Eventually, the addicted person comes to believe the denial. The alcohol dependent individual may be ashamed and embarrassed about his alcoholic behavior. When these behaviors conflict with their moral values, suicide is a possibility. Some addicted persons become paranoid. Depression and extended periods of sadness and feelings of low self-esteem may also be experienced by the person who abuses alcohol.

Physical. In addition to the physical effects previously mentioned, other complications include: lowered resistance to infection, malnutrition as a result of not eating, lack of motivation because of being physically tired, reduced sex drive, and sleep disturbances. Other problems which may not be easily identified as alcohol-related may include: arm and leg muscle weakness, pneumonia, nerve damage, and irregular heart condition. Excessive use of alcohol may be the start of some physical problems. Existing problems are also made worse by alcoholism and alcohol abuse.

Alcohol and Medications. The inappropriate use of medications and drinking alcohol may be a deadly combination for the elderly adult. Combining alcohol and medications is not a good practice at any age. It is especially dangerous for elderly persons to take their prescription or OTC medications with alcohol. Some elderly adults use alcohol instead of medications despite the doctor's warnings. The elderly adult generally will be taking several different kinds of drugs, and alcohol tends to block, change, or increase the desired effects of the medication. Alcohol addiction may also cause the individual to stop taking a needed medication. The end result could be misuse, overuse, overdose or death.

Brain Impairment. Brain damage resulting from excessive use of alcohol is often blamed on the aging process. However, dementia is not a normal condition of aging. While older adults may experience some memory loss, most of them remember names, events, and situations, and are able to solve problems and learn new information. What they may require, however, is a little more time and a few more cues to accomplish the task.

The functional abilities (thinking, judging, decision-making and memory) of the older adult are affected by excessive drinking. The personality (the tendency to be passive, controlling, angry, rigid, blaming, submissive, etc.) may be influenced. Since other diseases may affect functional abilities and personality, recognizing the underlying cause may not be easy.

Changes in the elderly adult's physical, mental or emotional condition because of alcohol dependency, may have occurred gradually. They may have gone unnoticed by family members until the decline in the level of functioning was drastic.

Consistent alcohol abuse may cause the older adult to withdraw from some activities in which he or she was a regular participant. Family members will generally accept this behavior as characteristic of the normal aging process, rather than a sign of a problem with alcohol or another drug.

Alcoholism and alcohol abuse take a toll on the body of the elderly adult. However, even when noticeable brain damage has occurred, avoiding alcohol can result in improved brain functioning in some areas. The brain has the remarkable capacity to make new pathways to carry its messages and to take over functions of permanently damaged cells.

Substance Abuse Risk-Creating Issues For Black Caregivers

Lifestyle, social status and available economic resources can be powerful determinants of who may be at risk for alcoholism and drug abuse. However, Black people must be careful not to accept cultural factors as an excuse for the addiction of a loved one. On the other hand, specific culturally-based traditions and reactions to abuse and dependency can be essential to effective prevention, intervention or treatment.

One study of the social, political, and cultural forces that influence Black Americans (National Institute of Drug Abuse, 1980) concluded that: (1) No one set of psychological characteristics can be blamed for all addictions; and (2) All individuals who are addicted have significant personality factors. The most common personality factors include:

1) The need for immediate gratification and sensation;
2) A lack of commitment;
3) Non-conformity tendencies;
4) A display of anti-social behavior;

5) Alienation;
6) A lack of self-esteem;
7) Elevated level of stress; and
8) Marked depression

In addition to these characteristics, there are some cultural factors which suggest that: (1) Blacks are more likely to abuse alcohol; (2) They are less likely to receive treatment; and (3) When they do receive treatment, it is usually at a later stage in the disease. These factors include:

1) The history of racism in the United States psychologically handicaps the self-esteem of African Americans.
2) Poverty, unemployment, and lack of job and career opportunities intensify the constant struggle for survival and the need to be equal to others. The inability to adequately provide for loved ones causes hardship and personal conflict with the African American value system.
3) Using alcohol and other drugs seems to ease the frustrations of constantly being rejected by the world around them.
4) African American communities have more than their share of liquor establishments and liquor advertisements. Alcohol is portrayed as the mark of success. Black entertainment stars are used to glamorize drinking.
5) Blacks tolerate a high level of dysfunctional behavior, including public drunkenness, open drinking/drug use on the street, and weekend drinking parties.
6) There are no clear social norms, expectations, or sanctions to regulate appropriate alcohol consumption, acceptable and unacceptable behavior when drinking, or the appropriate social or religious, ritualistic role of drinking.
7) Blacks receive misinformation about alcohol and drug programs, which leaves them with negative feelings about the nature and value of treatment.
8) There is a fear among the more educated Blacks that their social standing in the White community is keyed to their use of alcohol.
9) Denial of pain, frustration and other problems is compounded among Blacks who fear a confirmation of alleged inferiority.

The African American Family in Recovery

It is the tradition of the African-American family to work as a unit for the good of all its members. The family's strength is rooted in its ability to successfully cope with a history of oppression, racism, and economic disparity from the larger society. As a people, African-Americans have successfully used the legal system to fight for rights as United States citizens; yet, they have not been as successful in their efforts to deal with the alcohol and drug problem that threatens the family.

Several reasons are offered for this apparent failure:

1) Lack of community standards, sanctions or consistency of expectations;
2) Aggressive marketing by the alcohol industry within the Black community;
3) Rejection of the idea that alcoholism is a disease among the Black community as a whole;
4) Lack of resources available to the Black community to counter the effects of addiction;
5) Denial that a problem exists; and
6) Distrust of the majority society which offers and controls the available services or resources.

These barriers must be overcome by the African American family caregiver. The strength of the family must be acknowledged and used to reach the addicted family member. The family's alcoholic involvement can no longer remain a secret in an attempt to avoid personal pain or escape additional harm by the White system. To help the addicted individual, the caregiver must reject the negative images held by the larger society. The caregiver has an obligation to access the services available and needed by the addicted family member. The caregiver should also sensitize the service providers contacted to the needs of the substance abuser, as well as the family.

African-American caregivers can better help addicted family members by accepting their own risk for the disease, and learning how that disease progresses. It is equally important not to excuse the behavior resulting from addiction. Caregivers should strive to understand and sympathize with the addicted person's lack of control. Addiction takes control of the person's life; the disease continues to get worse if not treated, and the end result is death.

In the face of addiction, some family caregivers will feel powerless and will attempt to make life easier for the substance abuser while denying the powerlessness they feel. Sometimes the family member appears to choose the alcohol over the caregiver's love and attention. This natural, for the caregiver feels anger and rejection and believes that the addicted member does not appreciate his effort. When other family members assume the responsibilities of the addict, the individual doesn't have to face the negative consequences of their behavior.

The addiction continues and the addicted member is rewarded for undesirable behavior. Families must be careful not to fall into the trap of enabling. Enabling occurs when the addict's behavior is sanctioned by others. Enabling can be a conscious act, e.g., by covering up or assuming responsibility for the alcohol dependent person. It may also be unconscious, e.g., when caregivers give up and assume that there is nothing they can do to help the addict. Some examples of family caregiver behavior that are considered enabling are:

1) Making excuses for the addict;
2) Accepting responsibility for the addict's problems;
3) Failing to confront the addict; and
4) Allowing the addict to be abusive to other family members.

Assuming responsibility for another's problems when there is no control and no ability to fix the problems, creates pain, anger and sadness for the caregiver. The feelings must be addressed in a healthy way, preferably by involving the addict in problem-solving.

Caregivers must learn to make decisions based on their own needs and behavior, rather than attempting to change the behavior of the addict. Although the caregivers may have no control over the behavior of the addict, changing their own behavior can reduce the amount of control addicts exert over their caregivers. Detaching from the addict allows him to experience the consequences of his undesirable behavior. It does not mean that the caregiver loves the family member any less; rather, it forces the addicted family member to accept some responsibility for his actions and to help himself.

The time is now for the African American family to take a risk and become involved with the problem that threatens its future. Individuals must overcome their distrust of a system that has caused them pain in the past. Families must learn to take from the system the help that is available, instead of avoiding the system entirely. Addiction is a family illness, and family members experience some of the same effects as the addicted member. Sharing and discussing feelings about the family's experiences with addiction may provide the caregiver with new coping skills to help the individual and the family to recover.

These messages apply equally to the caregiver who may be abusing alcohol or may become alcohol dependent as a response to the strains of caregiving. Many people turn to alcohol and other drugs as a way of trying to cope with feelings of stress. The use of alcohol however, is a poor and often destructive means of coping.

Fortunately, assistance is frequently available for those wishing to break through the cycle of addiction. Caregivers experiencing problems with substance abuse may wish to consult with a trusted minister, pastoral counselor, physician, or pharmacist, or with someone currently in recovery from an alcohol problem.

Treatment resources which may be available include: Twelve-Step oriented support groups such as Alcoholics Anonymous, community mental health centers, substance abuse treatment programs (inpatient and/or outpatient) and licensed private counselors. It should be cautioned, however, that there will be variation in the degree to which individuals and programs are sensitive to issues of age and culture. Recently, there have been new opportunities for social service agency employees to get special training in cultural competence and multicultural awareness. Caregivers should seek assistance from providers who either have experience working with African American families, or have participated in these training opportunities.

AUDIO-VISUAL REINFORCEMENTS:

"A Thin Line: Recognizing Cultural Differences in Chemically Dependent Black Clients," produced and distributed by the Institute on Black Chemical Abuse, 2616 Nicollet Avenue, South, Minneapolis, MN 55408, (612) 871-7878

"Message of Concern: Alcoholism and The Older Adult," produced by Virginia Commonwealth University. Distributed by the Virginia Department for the Aging, 700 E. Franklin St., 10th Floor, Richmond, VA 23219-2327, (804) 225-2271.

EXPERIENTIAL LEARNING:

1) At the end of this module is a quiz on alcohol problems in later life. Have participants complete the quiz and use items as stimulus for discussion. The answers to the true-false statements and a brief explanation are also provided.

2) In small group settings develop strategies for involving the family in the treatment program of an addicted family member. Participants may wish to role play a family situation where one member is addicted to alcohol and problem solve how to get the addicted family member into an appropriate treatment setting and recovery.

3) At the end of this module is a handout from the National Institute on Aging. Distribute copies of the handout, and discuss detecting drinking problems among older adults and resources available for caregivers.

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QUIZ ON ALCOHOL PROBLEMS IN LATER LIFE

1) It is easier to detect an alcohol problem in an older person than it is in a younger adult.

2) Medications usually reduce the effects of alcohol in older persons.

3) Women with alcohol problems tend to be more secretive about their drinking than men are.

4) In older people, the central nervous system is usually very sensitive to the depressant effect of alcohol.

5) Signs of alcohol problems in older persons are often mistaken for signs of aging or chronic illness.

6) Older people are more likely than younger adults to admit to having an alcohol problem.

7) Alcohol problems in later life increase the chance of suicide.

8) Alcohol is a stimulant and makes older persons feel younger and more energetic.

9) A person must want to stop drinking before he or she can be helped to stop.

10) The same amount of alcohol usually has a greater effect on older adults than on younger adults.

Pratt, C. C., Wilson, W., Benthin, A., & Schmall, V. (1992). Alcohol problems and depression in later life: Development of two knowledge quizzes. The Gerontologist, 32 (2), 175-183.

QUIZ ON ALCOHOL PROBLEMS IN LATER LIFE (Answers)

1. It is easier to detect an alcohol problem in an older person than it is in a younger adult. ***(False)***
Alcohol abuse in later life is often hidden and, consequently, overlooked. Most older people are retired and don't have work problems caused by alcohol use; they often live alone; and they usually drink in the privacy of their homes and so are less likely to be disruptive in public or arrested for driving while intoxicated. Also most instruments used to evaluate potential alcohol abuse use indicators that are not as relevant to an older person.

2. Medications usually reduce the effects of alcohol in older persons. ***(False)***
Prescribed and over-the-counter medications can intensify the effects of alcohol, leading to more rapid intoxication and intensifying the dangers associated with alcohol use. For example, when alcohol is taken with sedatives, tranquilizers, hypnotics, and pain relievers, there is cumulative depressant effect on the central nervous system.

3. Women with alcohol problems tend to be more secretive about their drinking than are men. ***(True)***
Society places a greater stigma on women who abuse alcohol, so women may hide their drinking more and feel greater shame and guilt.

4. In older people, the central nervous system is usually very sensitive to the depressant effect of alcohol. ***(True)***
The central nervous system is especially sensitive to the effects of alcohol. The effects are often subtle and are sometimes mistaken for senile dementia in an older person.

5. Signs of alcohol problems in older persons are often mistaken for signs of aging or chronic illness. ***(True)***
The physical and psychological symptoms of alcohol abuse are sometimes mistaken for signs of aging and/or physical illness. Alcohol dependence can present as almost any medical illness, and medical problems also can mask alcohol dependence.

6. Older people are more likely than younger adults to admit to having an alcohol problem. ***(False)***
An alcohol problem is often a strong moral issue for older persons. Feelings of shame, guilt, and stigma are greater and more ingrained than in many younger adults. As a result, denial is often strongest with older persons and the amount of alcohol consumed is more likely to be underreported.

7. Alcohol problems in later life increase the chance of suicide. ***(True)***
The risk for suicide is particularly high for older white males who live alone and have a history of alcohol use.

8. Alcohol is a stimulant and makes older persons feel younger and more energetic. ***(False)***
Alcohol is not an effective "mood lifter." It depresses the central nervous system, causing or intensifying depression and impairing mental alertness, judgment, memory, and physical coordination.

9. A person must want to stop drinking before he or she can be helped to stop. ***(False)***
A person does not have to want to stop drinking, admit he or she is an alcoholic, or "hit bottom" before he or she can be helped. One of the symptoms of alcoholism is the inability of the afflicted to recognize its severity. Many people with an alcohol problem can be persuaded to seek treatment through a process called "intervention" in which the problem is directly confronted.

10. The same amount of alcohol usually has a greater effect on older adults than on younger adults. ***(True)***
Because of several bodily changes, alcohol is metabolized and excreted at a slower rate in the older person. As a result, a given amount of alcohol results in higher blood alcohol level and quicker intoxication for an older adult than for a younger adult.

Pratt, C. C., Wilson, W., Benthin, A., & Schmall, V. (1992). Alcohol problems and depression in later life: Development of two knowledge quizzes. The Gerontologist, 32 (2), 175-183.

National Institute on Aging

Age Page

Aging and Alcohol Abuse

Alcohol abuse among older men and women is a more serious problem than people realize. Until recently, older problem drinkers tended to be ignored by both health professionals and the general public. The neglect occurred for several reasons: few of our older population were identified as alcoholics; chronic problem drinkers (those who abused alcohol off and on for most of their lives) often died before old age; and because they are often retired or have fewer social contacts, older people are often able to hide drinking problems.

More people are learning that alcohol problems can be successfully treated at any age, and more are willing to seek help to stop their drinking.

Physical Effects of Alcohol

Alcohol slows down brain activity. It impairs mental alertness, judgment, physical coordination, and reaction time—increasing the risk of falls and accidents.

Over time, heavy drinking can cause permanent damage to the brain and central nervous system, as well as to the liver, heart, kidneys, and stomach.

Alcohol can affect the body in unusual ways, making some medical problems difficult to diagnose. For example, the effect of alcohol on the cardiovascular system (the heart and blood vessels) includes masking pain that might otherwise serve as a warning sign of heart attack. Alcoholism can also produce symptoms similar to those of dementia: forgetfulness, reduced attention, and confusion.

Mixing Drugs

Alcohol, itself a drug, is often harmful if mixed with other drugs, including those sold by prescription and those bought over-the-counter. People over 65 run the greatest risk of a bad drug interaction since they make up 12 percent of the population and take 25 percent of all medications. Also, older Americans are heavy users of over-the-counter drugs.

Mixing drugs—such as alcohol, tranquilizers, sleeping pills, pain killers, and antihistamines—can be very dangerous. For example, aspirin in some people causes bleeding in the stomach and intestines. Alcohol also irritates the stomach and, when combined with aspirin, may increase the risk of bleeding.

With advancing age, major changes occur in the body's ability to absorb and dispose of drugs and alcohol. Anyone who drinks—even moderately—should check with a doctor or pharmacist about possible drug interactions.

Who Becomes a Problem Drinker?

In old age, problem drinkers seem to be one of two types. The first are chronic abusers, those who have used alcohol heavily for many years. Although most chronic abusers die by middle age, some survive into old age. Approximately two-thirds of older alcoholics are in this group.

The second type begins excessive drinking late in life, often in response to "situational" factors: retirement, lowered income, declining health, loneliness, or the deaths of friends and loved ones. In these cases, alcohol is first used for temporary relief but later becomes a problem.

Detecting Drinking Problems

Not everyone who drinks regularly or heavily is an alcohol abuser, but the following actions indicate a problem:

- Drinking to calm nerves, forget worries, or reduce depression
- Losing interest in food
- Gulping drinks and drinking too fast
- Lying about drinking habits
- Drinking alone with increased frequency
- Injuring oneself, or someone else, while intoxicated
- Getting drunk often (more than three or four times in the past year)
- Needing to drink increasing amounts of alcohol to get the desired effect
- Frequently acting irritable, resentful, or unreasonable during nondrinking periods
- Experiencing medical, social, or financial problems that are caused by drinking.

Getting Help

Older problem drinkers and alcoholics have an unusually good chance for recovery because they tend to stay with treatment programs.

Getting help can begin with a family doctor or member of the clergy, through a local health department or social services agency, or with one of the following organizations:

Alcoholics Anonymous is a voluntary fellowship of alcoholics whose purpose is to help themselves and each other get—and stay—sober. For information, call your local chapter or write to the national office at P.O. Box 459, Grand Central Station, New York, NY 10163. The AA can also send you their free pamphlet, *Time to Start Living.*

The National Clearinghouse for Alcohol and Drug Abuse Information is a Federal information service that answers public inquiries, distributes written materials, and conducts literature searches. Write to them at P.O. Box 2345, Rockville, MD 20852.

The National Council on Alcoholism and Drug Dependence, Inc., can refer you to treatment services in your area. Write to the national headquarters at 12 West 21st Street, New York, NY 10010; or call (800) NCA-CALL.

The National Institute on Aging offers a variety of resources on aging. Write to the NIA Information Center, P.O. Box 8057, Gaithersburg, MD 20898-8057.

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The Later Stages

Module 18: Maintaining Urinary Continence
Module 19: 24 Hour Care

Module 18: Maintaining Urinary Continence

GOAL: To provide accurate and helpful information to the caregiver on incontinence, a neglected, poorly understood and poorly managed condition.

RATIONALE: Urinary continence, the ability to maintain control of the bladder and urine flow, is a normal function learned early in life. When the control of urine flow is affected, incontinence usually results. Incontinence can be treated by medication, exercise, retraining, and learning the signals of the person who receives care. Importantly, incontinence is NOT part of the process of aging.

EDUCATIONAL OBJECTIVES: At the completion of this module, caregivers should be able to:

1) Identify three causes of urinary incontinence.
2) State four consequences of urinary incontinence.
3) Discuss three helpful actions which can improve or correct urinary incontinence.

MINI-LECTURE:

Continence (pronounced, CON-ti-nents) is the ability to maintain and retain bladder control. There is nothing in the normal processes of aging that causes a loss of urine control. Nevertheless, one of the most widely feared and disturbing concerns of aging individuals is the occurrence of urinary incontinence (pronounced, in-CON-ti-nents). Incontinence is the involuntary or unintentional loss of urine. Incontinence due to restricted mobility of the person with dementia or the failure of caregivers to provide toileting conveniences is not correctly termed. Although urinary incontinence is common among older men and women, aging alone does not cause urinary incontinence.

Incontinence presents many complicating factors for the older adult physically, psychologically, socially and economically. **Physical** factors (e.g., immobility, vision loss, impaction of the stool, inability to remove clothing in time, or inaccessibility to a bathroom) play an important part in increasing the frequency of incontinent events. Changes in the amount of urine the normal bladder can hold, the amount of fluid one consumes, and the ability of the bladder to interpret the voiding signals the brain sends affect episodes of incontinence.

There are also **psychosocial** factors affected by incontinence. Many people bothered with incontinence are embarrassed. They may withdraw from social contacts, make sure they are always close to the bathroom, or have difficulty communicating or recognizing their need to urinate. Urinary incontinence is a significant factor in determining whether a person can be cared for at home, or whether nursing home placement is advisable. Depression may be an outcome of rejection, embarrassment, and withdrawal in the person experiencing urinary incontinence.

Viewing urinary incontinence from the standpoint of pure **economics**, the equipment and materials needed to meet the demand for care (e.g., adequate changes of clothing, protective padding, a change of rooms closer to the bathroom, odor removers and other costly items) must be weighted against the cost of placing a loved one in a nursing home. Therefore, measures to control incontinence as much as possible, must be identified and used. The ability of the person with dementia to remain continent has been lost. As a consequence, the burden of care to meet this need is shifted to the home caregiver. The person with advanced dementia of the Alzheimer's type who is incontinent is often a likely candidate for nursing home placement.

The risks of urinary incontinence increase as we age. Vigilance and the use of precautionary measures must be taken to prevent skin breakdown, pressure sores, urinary tract infections (from catheters) and depression. This is true whether the person is at home or in a nursing home facility. Urinary tract infections are usually major culprits contributing to incontinence, because older persons, especially persons with dementia, are more susceptible. One of the most common symptoms of urinary tract infections is acute confusion.

Many elders may forget to drink enough fluid to keep the kidneys functioning properly, and consequently may become dehydrated. Adequate fluid intake is extremely important, as are normal bowel movements and good nutrition. Unfortunately, these basic needs are often overlooked by caregivers because the cues given by the person cared for are not recognized. Similarly, hospitalization can be a frightening experience for older persons -- more so when the person has a mental disorder -- and they may overlook adequate fluid intake.

Medicine is often used to control incontinence and, generally, very effectively. However, a medication used to calm an anxious person can also restrict the flow of urine. On the other hand, medications used to control blood pressure often contribute to involuntary urination. A good example of a drug which would cause one to make frequent voiding (urinating) trips to the bathroom is the "fluid" pill. The pill may be discontinued in an effort to reduce the chance of incontinence. In fact, this is the purpose of the medication, to rid the body of excess fluid.

Safety is one more risk that needs to be considered in caring for the person with dementia. Wandering, hurrying to the bathroom, slipping in a urine puddle, stumbling over an irritating and uncomfortable incontinent pad discarded on the floor by the person being cared for, and inadequate lighting, can contribute to the potential for falls. Falls, especially when they result in bone fractures, are costly and often the result of inattention or carelessness.

Pearls of Wisdom for the Caregiver (Dippel & Hutton, 1988)

To improve continence care for the person with dementia:

1) Recognize that impairment and disorientation will affect how a person responds to the need to urinate.
2) Be simple, direct and brief when speaking; take your time so the person can follow your directions.
3) Make adjustments in the bathroom, e.g., hand rails, raised toilet seat or commode.
4) Note changes in bowel habits, (e.g., diarrhea, constipation,) and take steps to correct the condition.
5) Keep an accurate check on the amount of fluid the individual drinks. Six to eight glasses of water should be consumed daily, unless otherwise directed. It is helpful to provide the bulk of fluids during the daytime and evening hours.
6) Identify the bathroom with a large picture of a toilet, put the word toilet in large letters, or use other symbols that the person with dementia can recognize.
7) Provide adequate lighting at all times, particularly in the bathroom, so that the bathroom is easier to find during the night.
8) Suggest with words or gestures that it is time to go to the bathroom.
9) Observe for restlessness; it may be a cue that the person has to go to the bathroom - or may already have gone.
10) Keep bowels open and active to avoid constipation.
11) Maintain the best hygiene possible, particularly if incontinent pants are worn, to prevent skin breakdown.
12) Develop a consistent toileting schedule based on the person's usual times to pass urine.
13) Always have symptoms of urinary infection checked by your health professional.

Persons with dementia are often unable to communicate their daily needs for urinating. They may instead exhibit subtle behavior (e.g., restlessness, facial expressions, withdrawal when touched, or changes in body function). It is extremely important for caregivers to learn the communication signals of the person they care for. By doing so they can meet the needs of their care recipient safely and in a timely manner, while also attending to the person's individuality, independence, freedom and dignity (Eliopoulos, 1993).

EXPERIENTIAL LEARNING:

1) Re-enact some functional causes of incontinence. Develop a sensitivity session with a group of caregivers, using such props as blindfolds to make your way to the bathroom, sitting in a moist chair for a certain length of time, wearing incontinent pants (just getting them on correctly is an experience), sitting away from the group, or restrained. It is a must that you provide time after this activity for everyone to discuss what they saw, how they felt, and how these situations could be avoided. Surely you could think of other ways to re-enact some of the information provided in this module. Be creative!

2) At the end of this module is a handout from the National Institute on Aging. Distribute copies of the handout, and review the types of incontinence and treatment options with participants.

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Barbara A. Brant is gratefully acknowledged as the major contributor to this module.

National Institute on Aging

Age Page

Urinary Incontinence

Loss of urine control, or urinary incontinence (in-CON-ti-nents), occurs in people of all ages, but is particularly common in older people. At least 1 in 10 persons age 65 or older suffers from incontinence. This condition can range from the discomfort of slight losses of urine to the disability and shame of severe, frequent wetting.

Persons with incontinence often withdraw from social life and try to hide the problem from their family, friends, and even their doctor. The relatives of a person with incontinence often do not know about the choices of treatment and may believe that nursing home care is the only option.

These reactions are unfortunate because in many cases incontinence can be treated and controlled, if not cured. Incontinence is not an inevitable result of aging. It is caused by specific changes in body function that often result from diseases or use of medications. If untreated, incontinence can increase the chance of skin irritation and might raise the risk of developing bedsores.

Persons who have problems controlling urine should seek prompt medical care to determine the cause and lessen the chance of other problems. Even when incontinence cannot be completely cured, modern products and ways of managing the condition can ease the discomfort and inconvenience it causes.

Incontinence may be brought on by an illness accompanied by fatigue, confusion, or hospital admission. Incontinence is sometimes the first and only symptom of a urinary tract infection. Curing the illness usually will relieve or clear up the incontinence.

Types of Incontinence

The most common forms of urinary incontinence are listed below.

- **Stress incontinence** is the leakage of urine during exercise, coughing, sneezing, laughing, lifting heavy objects, or other body movements that put pressure on the bladder. It occurs most often in women.
- **Urge incontinence** is the inability to hold urine long enough to reach a toilet. It is often found in people who have conditions such as stroke, dementia, Parkinson's disease, and multiple sclerosis, but it can occur in otherwise healthy older persons.
- **Overflow incontinence** is the leakage of small amounts of urine from a bladder that is always full. In older men, this type of incontinence occurs when an enlarged prostate blocks the flow of urine from the bladder. Another cause is loss of normal bladder contractions in some people with diabetes.
- **Functional incontinence** occurs in many older people who have normal urine control but who have difficulty reaching a toilet in time because of arthritis or other crippling disorders.

Diagnosis

The first and most important step in treating incontinence is to see a doctor for a complete medical examination. This generally involves giving a detailed history of health and related problems, as well as undergoing a physical examination that focuses on the urinary and nervous systems and reproductive organs. The doctor will probably also want to check urine samples. In many cases, patients will then be referred to a urologist, a doctor who specializes in diseases of the urinary tract.

Treatment

Treatment of urinary incontinence should be tailored to each patient's needs. As a general rule, the least dangerous procedures should be tried first. The many options include:

- Certain behavioral techniques—including scheduled voiding, pelvic muscle exercises, and biofeedback—have been shown in recent studies to be very effective in reducing episodes of stress and urge incontinence.
- A number of medications can be used to treat incontinence. However, these drugs may cause side effects such as a dry mouth, eye problems, and buildup of urine; therefore, they must be used carefully under a doctor's supervision.
- Several types of surgery can improve or even cure incontinence that is related to a structural problem such as an abnormally positioned bladder or blockage due to an enlarged prostate. Artificial devices that replace or aid the muscles controlling urine flow have been tried in persons with incontinence. Many of these devices require surgical implantation.

Management

Sometimes incontinence cannot be cured, but it can be managed in several ways.

- Specially designed absorbent underclothing is available. Many of these garments are no more bulky than normal underwear, can be worn easily under everyday clothing, and free a person from the discomfort and embarrassment of incontinence.
- Incontinence may be managed by inserting a flexible tube known as a catheter into the urethra and collecting the urine into a container. However, long-term catheterization—although sometimes necessary—creates many problems, including urinary infections. In men, an alternative to the indwelling catheter is an external collecting device. This is fitted over the penis and connected to a drainage bag.

It is important to remember that incontinence can be treated and often cured. Even incurable problems can be managed to reduce complications, anxiety, and stress. When treatment is not completely successful, management plans can help many persons with incontinence.

Resources

For more information about incontinence, contact the following: Help for Incontinent People, (P.O. Box 544A, Union, SC 29379), the Simon Foundation for Continence (P.O. Box 835, Wilmette, IL 60091), and the National Kidney and Urologic Diseases Information Clearinghouse (P.O. Box NKUDIC, Bethesda, MD 20892).

For more information about health and aging, write to the National Institute on Aging Information Center, P.O. Box 8057, Gaithersburg, MD 20898-8057. The NIA distributes free *Age Pages* on a number of topics.

1991

Module 19: 24 Hour Care

GOAL: To enable caregivers to make an educated decision about nursing home placement.

RATIONALE: When caregivers know how to approach the nursing home decision, placement can be made in an informed manner that is beneficial to the family as well as the person with AD or dementia.

EDUCATIONAL OBJECTIVES: At the end of this module, caregivers should be able to:

1) Assess financial obligations involved in placement.
2) Evaluate the options offered by different facilities.
3) Decide when placement is necessary.
4) Deal with feelings of guilt and anger which are often associated with the move into a nursing home.
5) Develop a working relationship with nursing home personnel.

MINI-LECTURE:

When caregivers first contemplate the possibility of nursing home or other residential placement for their loved one with Alzheimer's Disease, what is the natural reaction? It is usually, "I'll never allow my loved one to be placed in a nursing home." This may be because nursing homes are often viewed as undesirable places to live. Families may feel that they have failed at caregiving if they choose nursing home placement. Caregivers also have many questions such as:

How will we pay for nursing home care?
When should we consider placement?
How will our loved one react?
How do we know which facility is best?
Where do we find a facility?
How will we ever adjust to our decision?

This module was designed to help answer these and similar questions.

Financial Matters

Financing long-term care is a complex and expensive process. A study conducted between 1988 and 1990 by the University of California found that caring for an institutionalized patient costs $47,591 a year (Aging News Alert, 1993). Careful arrangements for payment should be made well in advance to insure that long-term care is available and affordable when the time comes. To understand Medicare and Medicaid funding policies, it's important to distinguish between the different levels of care.

Custodial Care. Custodial care helps a person perform activities of daily living, which include assistance with bathing, eating, dressing, and other routine activities. It is usually given by people without medical training. It is less intensive than the higher levels of care and can be provided in many settings, including nursing homes, adult care residences and at home. Sometimes custodial care is called personal care (National Association of Insurance Commissioners, 1993).

Intermediate Nursing Care. Intermediate nursing facility (INF) care is needed for stable conditions that require daily, but not 24-hour nursing supervision. Such care is ordered by a physician and supervised by registered nurses. Intermediate care is less specialized than skilled nursing care and often involves more personal care. Intermediate care is generally needed for an extended time (National Association of Insurance Commissioners, 1993).

Skilled Nursing Facility Care. A skilled nursing facility (SNF) furnishes skilled nursing and rehabilitation services primarily (U.S. Department of Health and Human Services, 1992). A SNF is what is commonly thought of as a nursing home. Often, people choose a nursing home with multiple levels of care so that their loved one can remain in the same facility.

Beyond the individual's personal resources and any long-term care insurance that may have been purchased, there are several ways to pay for residential and nursing costs. Medicare, Medicaid, and other benefits can make the burden of paying easier for qualified indigent persons (see Caregiver Plan on Formal Supports and Resources).

Medicare. As of 1993, Medicare pays for 100 days of care in a SNF after a hospital stay of at least three days. The first 20 days are paid completely. The next 80 days are partially paid by Medicare and the patient pays a co-insurance charge of $84.50 a day. To be eligible for Medicare coverage, individuals must:

1) Require continued treatment of the condition for which they were hospitalized and their admission is within 30 days of discharge from the hospital;

2) Require skilled nursing or skilled rehabilitation (physical therapy, speech therapy or occupational therapy) services that must be performed or supervised by professionals and their physician certified this need; or

3) Require these skilled services on a daily basis.

Medicare will not pay for SNF care if the services received are primarily personal care or custodial services, such as, assistance in walking, getting in and out of bed, eating, dressing, bathing, and taking medicine (U.S. Department of Health and Human Services, 1993; See Caregiver Lesson Plan on Formal Supports and Resources regarding Part A and Part B of Medicare). This is of real concern to persons with Alzheimer's Disease and their families because these custodial services are needed more often than skilled nursing care.

Medicaid. The first step to take in determining eligibility for Medicaid is a visit to your local Department of Social Services. The first source of payment for nursing home care is your own savings, pensions, health insurance and social security. Medicaid pays only after your eligibility has been confirmed. To be eligible for Medicaid, the patient must "spend down" the bulk of their assets, with the exception of their home. The spouse may continue to receive Social Security Income. Recently, Medicaid law been changed to include "spousal impoverishment provisions." These provide some protection of income and resources for a spouse still living at home when the other partner needs nursing home placement (U.S. Department of Health and Human Services, 1992).

When you begin considering the idea of placing your loved one in a facility, visit those in your area. Pick up admissions packets which should include a detailed written agreement about charges and services. This is signed by someone in the facility with the authority to make a contract. The agreement should say what regular extra charges you can expect to pay (e.g., hair care, personal laundry service, physical therapy, etc.). Beyond this, you should receive a list of charges for all additional services available.

The financial agreement should also cover such areas as (Mace & Rabins, 1981):

1) Will the patient receive a refund of advance payments if he leaves the facility?

2) How are cash and assets that have been entrusted to the home protected? Is a receipt given to the patient? Are withdrawals noted by signed receipt, so that you or the resident can keep track of their account?

3) Are the agreed date of admission and the degree of care to be furnished set forth in the written agreement?

4) Under what circumstances can the home discharge a person, and how much notice must they give you?

5) Will the facility retain the person when his private funds are expended and he transfers his method of payment to Medicaid funding?

Generally residential facilities will expect you to pay in advance for the first month. You may want to see a lawyer about setting up a trust account. You may need to get agreements from members of the family about sharing in the cost of care (Caregivers practical help: Caring for Alzheimer's patients, 1988).

Evaluating Your Options

Once the financial situation has been assessed, the next important decision is where you will place your loved one. Some people who can provide guidance are your physician, clergy, family, friends, trusted health or social service professionals, nursing home advocacy organizations, the local nursing home ombudsman, and staff at the local Alzheimer's Association chapter. Area Agencies on Aging and local social service departments are good sources for information about the nursing homes in your area as well. Other sources of information include the following organizations (National Institute on Aging, 1992):

> The Nursing Home Information Service is an information and referral center for consumers. The Service provides information on nursing homes and alternative community and health services, including a free guide on how to select a nursing home. For more information, write to the National Council of Senior Citizens, Nursing Home Information Service, National Senior Citizens Education and Research Center, Inc., 1331 F Street, NW, Washington, DC 20004.
>
> The National Citizens Coalition for Nursing Home Reform helps local organizations work for nursing home reform and improvements in the long-term care system. To contact them, write to the national office at 1224 M Street NW, Suite 301, Washington, DC 20005.

The American Association of Retired Persons (AARP) and the American Association of Homes for the Aging (AAHA) have information on continuing care communities. Write to the AARP/Housing Activities, 601 E Street, NW, Washington, DC 20049; OR the AAHA, 901 E Street, NW, Suite 500, Washington, DC 20049.

There are many factors to consider when you are evaluating your options. Geographical location is very important since the distance between you and the facility can influence how often you visit your loved one. Nursing homes and other housing options (e.g., Homes for Adults, Retirement Communities, etc.) are listed in the Yellow Pages of your telephone book. Your local Area Agency on Aging may also be able to provide you with a list of housing options.

Be sure that the nursing homes you consider have the level of care that your loved one needs. You will also need to find out whether the nursing home will accept the funding sources you are planning to use. Proper physical and emotional care of their loved one is of utmost concern to families. Consider the nursing home's visiting hours. If visiting is restricted to only a few hours, you may wonder what goes on when you are not around. Are young children allowed to visit? Make sure there is a registered nurse (RN) or licensed practical nurse (LPN) on each shift. Observe the resident-to-aide ratio and the competence of staff members before you decide which facility to choose. Question the administration regarding the staff turnover to get an idea of the level of staff satisfaction. Happy personnel are less likely to take their personal frustrations out on residents. Families expect their loved ones to be treated with dignity and respect (Boyd, Frieden, Higley, & Spencer, 1989). You might want to make a few unannounced follow-up visits at various times of the day and evening to confirm that this is the best place for your loved one. This process of searching for the best placement can seem overwhelming at times. Involving someone you trust in the decision may help alleviate some of the anxiety you feel.

Deciding When Placement is Necessary

Carl has Alzheimer's Disease. He moved to a nursing home in March 1989. Prior to that time and early in the disease process, Barbara knew that eventually Carl would probably need nursing home care. She selected the home that she felt would best take care of him. Knowing when Carl should move was a difficult decision. She worried about the cost of the nursing home and the reactions of her husband's parents and their friends. Barbara did not want to wait until a crisis occurred to move Carl to a nursing home. To prepare, she made a list of potential situations that would prompt the decision. This list included *combativeness, sleeplessness, incontinence, and wandering away from the house (Sandstrom, 1992).*

When dealing with a disease that is progressive, it is difficult to decide when placement in a nursing home is warranted. It is very hard to watch a loved one go through the stages of this debilitating disease. A good indicator is when the responsibilities of caregiving reach the point that your own mental or physical health is jeopardized or threatened. Remember, "Love is doing what people need - not what they want" (Manning, 1983).

The right time for placement is a family decision and your decision should reflect the needs of the person and all family members involved (Mace & Rabins, 1981). The time before placement is a time to reflect: Can I give a task that has consumed my days and nights for so long, over to strangers? Consider that many people with AD will do better in a structured environment with caring professionals to provide physical, emotional, and social care (Warshauer, 1988). Will your loved one recognize a change in environment? Does he recognize you and other family members? Are you physically able to care for him? Could your loved one unintentionally harm himself or someone else if you continue to care for him? Would there be more stimulating activities and peer support in a nursing home than you can offer at home? These are all questions your family must consider before making a decision.

Every nursing home requires a medical evaluation prior to placement. The starting point for evaluation is a medical assessment which determines the level of care needed and establishes an agreeable plan of care. Find out if the nursing home at which you are applying can use only the doctors on staff at the facility. The resident's care will be governed by a specific plan of action. This plan is reviewed every three to six months. Families are encouraged to take part in care plan conferences to add important information about working with their loved one. The caregiver is an expert on the care needs of the impaired person. Be willing to share observations about your loved one's likes, dislikes, past and present interests, habits, and strengths and weaknesses. Put your observations in writing because this information can prove to be very beneficial to the staff involved in direct care for the person with Alzheimer's. Share with the staff little hints that you have learned in handling your loved one and let them know what you expect.

Dealing with the Feelings that Come with Placement

Upon admitting a loved one with Alzheimer's disease to a facility, the caregiver may have mixed feelings about placement. On the one hand, there may be an overwhelming sense of guilt, anger, and loneliness about having to leave their loved one in a strange place. On the other hand, the caregiver may be relieved to finally have time to engage in other activities that were precluded by caregiving responsibilities. The caregiver is dealing with many emotions, and each caregiver has a different way of coping with the adjustment. Residents seem to adjust better if they are allowed to bring familiar items from home such as a favorite piece of furniture or wall decoration. The caregiver should be closely involved with the adjustment process. Frequent visits are advisable. Telephone contact with the nursing or social work staff should be maintained between visits.

The "typical" person with AD may feel abandoned, lost, or "tricked" upon admission. He may be angry, suspicious, withdrawn, agitated, or afraid (Gwyther, 1988).

Ethel has Alzheimer's disease. Her daughter-in-law brought her to the nursing home in 1992. Ethel was in a state of confusion as she roamed the halls facing new people and new surroundings. A staff nurse showed her the way back to her room. Ethel screamed, "Take me home!" She was frightened by the unfamiliar surroundings. She hid behind her door and would not come out. A social worker arrived to gently coax her out from behind the door. Ethel stated, "Daddy's coming to get me soon, I have to be ready to go." She put on her hat and picked up her purse and headed down the hall. Ethel's daughter-in-law fortunately had a good sense of humor and she talked to the staff about how she handled Ethel's behavioral problems.

Many caregivers, particularly spouses, experience grief and bereavement over the loss. How well the caregiver copes depends on past relationships, their feelings about caregiving responsibilities, unresolved conflicts, and the support available both before and after placement (Ballard & Gwyther, 1990). Both the resident and family will need time to make the adjustment to the nursing home placement. Often family members will vent their frustrations by being rude to the staff. Experienced staff members will be understanding. They will devise ways to make the family feel useful and still involved with the resident's care. After the move, caregivers should realize that now they can have a life of their own and that now they can rest! The strong feelings of grief, sadness, anger, and loneliness can build during caregiving. Now that you are not providing what seems like 36-hour-a-day care, you can work through these feelings of bereavement. Other family, friends, doctors, counselors, and clergy can be an excellent source of support. Consider joining an Alzheimer's Association support group.

Developing a Partnership with Nursing Home Personnel

It's important for the caregiver to be aware of what particular job is performed by each member of the nursing staff. The caregiver can feel very uneasy about handing over their caregiving responsibility to someone they barely know. This discomfort can be gradually relieved as the caregiver becomes more familiar with the nursing home staff. The first step is understanding the various responsibilities of the staff.

The **nurse's aide** spends more time with the resident than any other health team member. The caregiver and the aide should become powerful allies in assuring the patient's care and sense of well-being. The **social worker** can help with dealing with feelings and can be a source of information for community resources. The **nursing home administrator**'s responsibility is to make sure that the home is running smoothly and that policy is being followed. The **charge nurse** is concerned mainly about the patient's health, emotional, and social well-being. All nursing homes will have access to a **physician** for acute medical problems and for monitoring the general well-being of residents. A **dietician** meets the nutritional needs of the resident by suggesting ways of handling mealtime difficulties. **Physical therapists** and **occupational therapists** can suggest therapeutic activities designed to increase or maintain certain physical functions. The **activity director** can provide recreational activity for your loved one (Ballard & Gwyther, 1990). As family members come to understand how things work at the facility, they begin to feel connected to the new caregiving situation. The relationships developed between the nursing home staff and the family caregiver can be the basis for open communication and informed care.

The nursing home staff can always use a word of encouragement, praise, and gratitude. When mutual feelings of respect exist between staff and family, the resident will reap the benefits. The staff will feel free to consult the family, and the family to consult the staff (Silverstone & Hyman, 1982). The family continues to play an active role in the lives of their loved ones with dementia. In some sense the family provides a link between the institutionalized persons and their community.

Making the decision to enter a nursing home is a very complex matter. It involves deciding how you can pay for it, where and when the placement will be made, how you are going to deal with the attendant emotional difficulties, and becoming familiar with the nursing home personnel.

AUDIO-VISUAL REINFORCEMENT:

"Where Do We Go From Here?" produced and distributed by Education Development Center, Inc., School and Society Programs, 55 Chapel St., Newton, MA 02160.

"My Mother, My Father" produced by James Vander Bosch. Distributed by Terra Nova Films, Inc., 9848 Winchester Ave., Chicago, IL 60643 (312) 881-8491.

EXPERIENTIAL LEARNING:

1) At the end of this module are two caregiver handouts which contain questions caregivers should ask themselves when choosing a nursing home placement. Distribute copies of the handouts and briefly review the kinds of considerations important in the placement decision.

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Sheryl Lutz is gratefully acknowledged as the major contributor to this module.

NURSING HOME CHECKLIST

(Adapted from Gwyther, 1988; Mace & Rabins, 1981).

When you are looking for an appropriate nursing home, there are a number of factors to be considered. The questions which follow concern the physical aspects of the facility, the services offered, and the atmosphere or attitudes of the staff.

Generally, the best nursing home is the one which yields the most "yes" answers to the questions asked. However different homes offer different services. You must decide which services are most important to you.

If the answer to any of the first four questions is "no," do not consider the facility for placement.

1. Does the home have a current license from the state?
2. Does the administrator have a current license from the state?
3. If you need and are eligible for financial assistance, is the home certified to participate in government or other programs that provide it?
4. Does the home provide special services such as a specific diet or therapy that meets the resident's needs?

PHYSICAL CONSIDERATIONS

5. Location
    - a. Pleasing to the person with AD?
    - b. Convenient for the resident's personal doctor?
    - c. Convenient for frequent visits?
    - d. Near a hospital?

6. Accident prevention
    - a. Well lighted inside?
    - b. Free of hazards underfoot?
    - c. Chairs sturdy and not easily tipped?
    - d. Warning signs posted around freshly waxed floors?
    - e. Handrails in hallways and grab bars in bathroom?

7. Fire safety
    - a. Meets federal and/or state codes?
    - b. Exits clearly marked and unobstructed?
    - c. Written emergency-evacuation plan?
    - d. Frequent fire drills?
    - e. Exit doors not locked on the inside?
    - f. Stairways enclosed and doors to stairways kept closed?

8. Bedrooms
    a. Open on to hall?
    b. Window?
    c. No more than four beds per room?
    d. Easy access to each bed?
    e. Drapery for each bed?
    f. Nurse call bell by each bed?
    g. Fresh drinking water at each bed?
    h. At least one comfortable chair per resident?
    i. Reading lights?
    j. Clothes closet and drawers?
    k. Room for a wheelchair to maneuver?
    l. Care used in selecting roommates?

9. Cleanliness
    a. Generally clean, even though it may have a lived-in look?
    b. Free of unpleasant odors?
    c. Incontinent persons are given prompt attention?

10. Lobby
    a. Is the atmosphere welcoming?
    b. If also a lounge, is it being used by residents?
    c. Furniture attractive and comfortable?
    d. Plants and flowers?
    e. Certificates and licenses on display?

11. Hallways
    a. Large enough for two wheelchairs to pass with ease?
    b. Hand-grip railing on the sides?

12. Dining room
    a. Attractive and inviting?
    b. Comfortable chairs and tables?
    c. Easy to move around in?
    d. Tables convenient for those in wheelchairs?
    e. Food tasty and attractively served?
    f. Meals match posted menu?
    g. Those needing help receiving it?

13. Kitchen
    a. Food preparation, dish washing, and garbage areas separated?
    b. Food needing refrigeration not standing on counters?
    c. Kitchen help observe sanitation rules?

14. Activity rooms
    a. Rooms available for residents' activities?
    b. Equipment (such as games, easels, yarn, kiln, etc.) available?
    c. Residents using equipment?

15. Special-purpose rooms
    a. Rooms set aside for physical examinations or therapy?
    b. Rooms being used for stated purpose?

16. Isolation room
    a. At least one bed and bathroom available for residents with contagious illness?

17. Toilet facilities
    a. Convenient to bedrooms?
    b. Easy for those with wheelchairs to use?
    c. Sink?
    d. Nurse call bell?
    e. Hand grips on or near toilets?
    f. Bathtubs and showers with non-slip surfaces?

18. Grounds
    a. Residents can get fresh air?
    b. Ramps to help handicapped?

SERVICES

19. Medical
    a. Physician available in emergency?
    b. Private physician allowed?
    c. Regular medical attention assured?
    d. Thorough physical immediately before or upon admission?
    e. Medical records and plan of care kept?
    f. Resident involved in developing plans of treatment?
    g. Other medical services (dentists, optometrists, etc.) available regularly?
    h. Freedom to purchase medicines outside home?

20. Hospitalization
    a. Arrangement with nearby hospital for transfer when necessary?

21. Nursing services
    a. RN responsible for nursing staff in a skilled nursing home?
    b. LPN on duty day and night in a skilled nursing home?
    c. Trained nurse's aides and orderlies on duty in homes providing some nursing care?

22. Rehabilitation - Physical therapy, speech therapy, occupational therapy
    a. Specialists in various therapies available when needed?

23. Activities program (Nursing home residents need structured programs such as music programs, recreation groups, and outings to keep them involved in interpersonal activities at the level of their abilities.)
    a. Individual preferences observed?
    b. Group and individual activities?
    c. Residents encouraged but not forced to participate?
    d. Outside trips for those who can go?
    e. Volunteers from the community work with residents?
    f. Is supervised daily exercise provided? Even wheelchair and bed patients need exercise, and those who can walk should be doing so. Exercise may reduce the restlessness of people with dementia.

24. Religious observances
    a. Arrangements made for a resident to worship as he or she pleases?
    b. Religious observances a matter of choice?

25. Social services
    a. Social worker available to help residents and families?

26. Food
    a. Dietitian plans menus or special diets?
    b. Variety from meal to meal?
    c. Meals served at normal times?
    d. Plenty of time for each meal?
    e. Snacks?
    f. Food delivered to the resident's room?
    g. Help with eating given when needed?

27. Grooming
    a. Barbers and beauticians available for men and women?

ATTITUDES AND ATMOSPHERE

28. General atmosphere friendly and supportive?

29. Residents retain human rights?
    a. May participate in planning treatment?
    b. Medical records are held confidential?
    c. Can veto experimental research?
    d. Have freedom and privacy to attend to personal needs?
    e. Married couples may share a room?

    - f. All have opportunities to socialize?
    - g. May manage own finances if capable or obtain accounting if not?
    - h. May decorate their own bedrooms?
    - i. May wear their own clothes?
    - j. May communicate with anyone without censorship?
    - k. Are not transferred or discharged arbitrarily?

30. Administrator and staff available to discuss problems?
    - a. Residents and relatives can discuss complaints without fear of reprisal?
    - b. Staff responds to calls quickly and courteously?

31. Residents appear alert unless very ill?

32. Visiting hours accommodate residents and relatives?

33. Civil rights regulations observed?

34. Visitors and volunteers pleased with home?

FAMILY GUIDE FOR CHOOSING A FACILITY FOR AN ALZHEIMER'S PATIENT

(Alzheimer's Association, 1992)

There are some additional considerations if you are thinking about placing a loved one with Alzheimer's disease in a residential setting. The Alzheimer's Association recommends that caregivers ask the following questions.

I. PHILOSOPHY - What is "special" Alzheimer care?

1. Does the Alzheimer care mission statement indicate benefits for you and your family member?
2. Are religious, cultural and unique advantages apparent for your family member?
3. Does the separated dementia unit or Alzheimer care program offer special advantages for your family member?
4. Does the facility have licenses you consider necessary? (State licensure, Medicare certification? Medicaid certification? Private accreditation which might include the Long-Term Care Council of the Joint Commission on Accreditation of Hospitals).

II. PRE-ADMISSION - Selecting a facility

5. Is a specialized Alzheimer/dementia care program available?
6. Is the facility location convenient for you?
7. Do you consider that the Alzheimer care program admission requirements are acceptable?
8. Do other residents have functional capabilities similar to those of your family member?
9. Is assessment done by staff to determine individual special (Alzheimer/dementia) care needs?
10. Is the program limited by discharge and/or transfer criteria?
11. Do you sense a caregiving partnership with facility staff?
12. Are residents rights addressed?
13. Is medical care and supervision sufficient?
14. Are behaviors accommodated without use of restraints?
15. Are fees and charges justified and competitive within your community?
16. Is Medicaid or other reimbursement available?

III. ADMISSION - Enter the facility

17. Do you feel support for your needs and concerns?
18. Are residents assisted by staff, volunteers and family?
19. Are advance directives (durable powers of attorney for health care and other determined instructions) discussed, documented and honored?
20. Is autopsy (for confirmation of diagnosis) discussed and family wishes honored?

IV. CARE PLANNING AND IMPLEMENTATION

21. Will you share in developing and reviewing an individualized care plan?
22. Is care planning done by an interdisciplinary care planning team?
23. Are care planning meetings held regularly and/or when needed to positively address care issues?
24. Is there a full daily schedule of therapeutic activities?
25. Are nutrition and eating needs of residents accommodated?

V. CHANGE IN CONDITION ISSUES

(Disease progression and other illness)

26. Will diminished abilities result in transfer or discharge from the program?
27. Is late stage care and illness addressed?

VI. STAFFING PATTERNS AND TRAINING

(Staff assignment and knowledge)

28. Do you feel confident and comfortable with staff leadership?
29. Is Alzheimer/dementia specific training available for all staff? (The staff needs to know how to manage catastrophic reactions, suspiciousness, wandering, etc.. If this training is not apparent, does the staff welcome information you may offer them?)
30. Does the number of staff appear adequate?
31. Are staff pleasant and encouraging to residents?
32. Is there competent monitoring of medical care?

VII. THE PHYSICAL ENVIRONMENT - A place for Alzheimer care

33. Is the environment safe and comfortable?
34. Does the size of the program offer benefits?
35. Is outdoor space available and used?
36. Is private space personalized and respected?
37. Is the environment calm and pleasurable?
38. Do safety measures meet the needs of your family member? (This includes sprinkler systems and fire doors in compliance with state fire regulations. Wanderers need to be protected from open doors and stairs.)

VIII. SUCCESS INDICATORS - Benefits of Alzheimer care

39. Do residents appear relaxed and content?
40. Are residents active and engaged in activities?
41. Is the atmosphere cheerful and homey?
42. Are residents clean and well groomed?
43. Do residents appear alert?
44. Are residents treated with dignity and respect?
45. Is restraint use absent or appropriate and closely monitored?
    (You may see people in restraint, but this should not be the usual way to manage behavior. Use of restraints over prolonged periods is rarely necessary. Many states have laws governing the use of restraints.)

46. Are privacy needs and confidentiality respected?
47. Is there open communication among residents, families and staff?
48. Are research opportunities explained?
49. Is the Alzheimer's care program objectively evaluated?
50. Are all aspects of care supervised and evaluated?

APPENDIX

I - About the Virginia Project

II - Synopsis of Replication Plan

III - Listing of Project Associates

A. Regional Needs and Resources Team - Central VA
B. Regional Needs and Resources Team - Southside VA
C. Trainers of Caregivers

I. About the Virginia Project

The operational focus of the Virginia Center on Aging (VCoA), a state agency, is applied gerontology, i.e., the translation of research to benefit real practice. Ongoing research and education emphases include: community-based supports in aging; multidisciplinary health care; and disabilities in aging, both lifelong (developmental) and late-onset. Consistent with these activities, the VCoA obtained funding from the U. S. Administration on Aging to pursue the project, "Assisting Caregivers of African-American and/or Rural Elders With Dementia: Progressive Training Through Trusted Resources." In cooperation with the Virginia Geriatric Education Center, the project became a guide and resource tool for training caregivers. The project aimed to identify rural and/or minority family members providing care for elders with dementia, and help them provide better care. In this way, the project hoped to improve eldercare services for rural and minority (primarily African American) elders with dementia in Central and Southside Virginia, the areas of the state targeted for the innovative project.

In the territory covered by the Alzheimer's Association - Greater Richmond Chapter (24 counties and 5 cities), there are approximately 18,000 persons with Alzheimer's Disease. The territory defined by the Southside Chapter (8 counties and 3 cities) has an estimated 4,080 people with AD. When taken together, these persons comprise about 22-25% of the state's estimated 88-100,000 persons with AD. Since four family members, on the average, are involved to some extent in caring for loved ones with AD, the number of Virginians affected by AD is much larger. African American and rural families were targeted by this project since they tend to under-utilize community services.

The project formed key partnerships with state and local agencies and other communities (such as faith communities) concerned with helping older Americans lead healthier lives. There were two groups of these partners, called Regional Needs and Resources Teams, one in Central Virginia, and the other in Southside. The most relevant and significant organizations that might address the continuing needs of African American and rural caregivers of elders with dementia were represented on these Regional Teams. The Teams advised project staff concerning the educational needs of caregivers and resources available in the targeted regions. Members of these teams provided continual guidance and assistance in the development of the training manual to assure that it was culturally sensitive and specific to the needs of the target populations. Key members from each Regional Team contributed Educational Chapters and Caregiver Lesson Plans. The Regional Needs and Resources Teams were also instrumental in the recruitment of potential trainers and caregiver participants.

An important part of this effort focused on the specific needs of minority and rural caregivers who may not have previously taken advantage of community resources for a variety of reasons. The Chapters on ethnic competence and rural considerations, as well as the Module on Formal Supports and Resources, were specifically designed to encourage the use of community services by minority and rural caregivers of older adults with dementia. The project also produced national, state, and local (Central and Southside Virginia) resource directories on diskette for trainers and others involved in assisting caregivers. (The National and Virginia State directories are available on diskette from the editors. See Order Form in back of manual.) In addition, caregiver participants were provided with an abbreviated directory of resources available in their own communities to encourage their utilization of formal services.

By reinforcing the basic family infrastructure and recognizing the desire for self-reliance, the project increased awareness of community services, decreased distrust of service providers, and improved caregiver knowledge and skills. The specific objectives and outcomes of the project are outlined below.

Objective I: To form a partnership of the most relevant and significant organizations that might address the continuing needs of Black and rural caregivers of elders with dementia, to be called Regional Needs and Resources Teams (RNRTs).

1. Regional Teams in Central and Southside Virginia were established and advised project staff concerning the educational needs of caregivers and resources available in the targeted regions. Members of these teams provided continual guidance and assistance in the development of the training manual, and recruitment of potential trainers.

2. Key members from each Regional Team reviewed the training manual to assure that it was culturally sensitive and specific to the needs of the target populations. Some of the members contributed modules to the manual, and others served as trainers of caregivers. RNRT members were especially helpful in recruiting both trainers and caregivers.

Objective II: To develop a comprehensive, culturally sensitive training package targeted to caregivers of elders with dementia that is organized according to the progression of cognitive, social, and behavioral impairment.

1. The training package consisted of this training manual, resource materials used during the two-day training sessions, a suggested reading list, and

Caregiver Resource Directories with listings particular to the targetted localities in Central and Southside Virginia.

2. The training manual explains in detail, exactly how to recruit caregivers, find a meeting site, and publicize the workshops. It provides step-by-step instruction on how to conduct caregiver workshops, and a Chapter on adult learning theory. There are 19 Caregiver Lesson Plans (modules), as well as evaluation instruments, and supplementary reading and reference lists for advanced preparation. Special Chapters on cultural sensitivity and outreach to African American and rural populations are included.

Objective III: To implement and test the "train-the-trainer" model as a mechanism for caregiver education.

1. The train-the-trainer approach was applied at the local community level to effect a large-scale increase in expertise and knowledge. Caregivers became more knowledgeable about dementia and available community resources, resulting in improved quality of life for caregiving families.

2. The project sought trainers of caregivers who were:
   (1) Knowledgeable of caregiver issues, especially caregiving for dementia victims,
   (2) In touch with caregiver networks locally (Area Agencies on Aging, Social Services, local Long Term Care Coordinating Committees, Alzheimer's Association chapters, faith communities, support groups, etc.),
   (3) Able to translate the training manual into a successful training experience for caregivers, and
   (4) Knowledgeable of caregiver training needs and means of recruiting potential caregiver trainees.

3. A total of 69 trainers were trained and formed teams to educate family caregivers. They spent 8.35 hours per trainer in contact with more than 175 family caregivers. In total trainers contributed 1,341.5 person-contact hours to the project, in addition to the effort required to recruit participants, organize and plan the workshops, and prepare Lesson Plans.

4. Project staff were continually available to aid in the recruitment of caregivers for trainers who had difficulty. Outreach social workers, Area Agencies on Aging staff, faith community leaders, and personal contacts were all ideal resources.

5. To enable and encourage attendance, the project reimbursed caregivers for adult day care, respite care, and transportation if needed. Trainers were also reimbursed for expenses incurred.

6. Caregivers were provided with a series of several workshops (generally, three) lasting between one and four hours each. Some workshops dealt with early issues, some with more problematic symptomology associated with the middle stages of dementia, and some provided information relevant to the late stages of dementia.

Objective IV: To evaluate the project and disseminate findings for replicability beyond the project period and beyond the geographical regions.

1. The project evaluated the effectiveness and utility of the two-day training sessions, demonstrating statistically significantly increases in knowledge among trainers ($p < .05$). The project staff also documented similar increases in knowledge among caregiver participants and summarized their evaluations of the workshop experiences. In addition, caregivers were surveyed regarding their particular caregiving situations in order to determine for whom the training is most effective.

2. Approximately 15% of the caregiver training sessions were monitored by project staff to ensure that the training package protocol was implemented properly.

3. The project has created a master plan for replication which will be disseminated through the Alzheimer's Association network, the Association for Gerontology and Human Development in Historically Black Colleges and Universities, Regional Administration on Aging offices, State and local human resource agencies, the Virginia Center on Aging, and the Virginia Geriatric Education Center.

In summary, the project was a train-the-trainer method of disseminating information to two under-served populations -- African American and rural caregivers. The primary products from the project were this training manual, two directories of resources (National and Virginia) on diskette, and a Replication Plan. Each of these products may be obtained by using the order form included at the back of the manual. A synopsis of the Replication Plan follows.

II. Synopsis of Replication Plan

The Replication Plan for the project, "Assisting Caregivers of Black and Rural Elders with Dementia: Progressive Training Through Trusted Resources," is based upon the Integrated Model for Collaborative Planning and Services to Older Adults with Developmental Disabilities, dubbed the Partners III Project, and directed by Edward F. Ansello, Ph.D. The Integrated Model is a broad, tested process strategy that is relevant for addressing the needs of people who live in the community rather than in institutional settings. The Integrated Model has three basic components which should be incorporated into any replication of this project. These are: 1) collaboration, 2) outreach, and 3) capacity-building. A brief discussion of these three outcomes provides a rationale for replicating the project.

Collaboration. One of the main objectives of the project was to form a partnership of the most relevant and significant organizations that might address the continuing needs of Black and rural caregivers of elders with dementia. These partners served a variety of functions for the project, from guiding the content of the training manual to recruitment of trainers and caregiver participants. Some partners served as first level trainers for the project, providing information about community resources and services available to caregivers, while others conducted caregiver workshops. In the process, agency representatives became better acquainted with others in the caregiving service network and begin to establish or further linkages for future resource sharing, referral, and collaboration.

Outreach. The need for outreach to rural and African American caregivers is well-documented in the manual's Chapters. The attendant barriers to service utilization among these two special populations, important considerations to any outreach effort, were addressed as the project sought to increase the likelihood that caregivers would access formal supports. Trainers were trained to function as advocates, in a sense, directing and guiding caregivers to those in their communities who could offer assistance. The outreach component of the project was further challenged by the colloquial stigma attached to dementia and Alzheimer's Disease. Yet, the project succeeded in identifying caregivers previously unknown to the local Alzheimer's Association Chapters and providing the foundation for the development of support groups in unserved communities.

Capacity-building. Another major objective of the project was to implement and test the "train-the-trainer" model as a mechanism for caregiver education. In accomplishing this objective the project directly developed the capacities of trusted community leaders who served as trainers of caregivers, indirectly improved the capacities of caregivers through the conduct of workshops, and subsequently increased the ability of elders with dementia to remain, as appropriate, in their communities and avoid premature institutionalization. The train-the-trainer model allowed for the expertise imparted to endure beyond the scope of the project with those in the community who were trained to conduct workshops, and empowered to do so via the training manual materials.

Those who replicate this project through the components of the Integrated Model will not only achieve these stated outcomes, but will also learn much about establishing linkages, networking in African American and rural communities, and developing community expertise to strengthen caregiving families.

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